

**Prevalence of depression and burden among informal caregivers of
people with dementia and the effectiveness of mindfulness and
acceptance based interventions at reducing these: two meta-analyses**

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Thesis portfolio abstract

The primary aims of this thesis were to examine the prevalence of depression and burden among informal caregivers of people with dementia (PwD) and the effectiveness of mindfulness and acceptance based interventions (MABIs) at reducing these difficulties. The thesis consists of a meta-analysis on the prevalence of depression and burden among informal caregivers of PwD, a bridging chapter detailing the rationale behind the second meta-analysis set within the context of the first, a meta-analysis on the effectiveness of MABIs on depressive symptoms and burden among informal caregivers of PwD, an additional methodology chapter on the random-effects model, and an overall discussion and critical appraisal. The first meta-analysis identified 43 studies, examining a total of 16 911 participants. The adjusted pooled prevalence of depression was 31.2% (95% CI 27.7% to 35.0%) and burden was 49.3% (95% CI 37.2% to 61.5%). The second meta-analysis included 12 studies, providing data on 321 caregivers. MABIs proved largely and moderately effective at reducing depressive symptoms and burden among informal caregivers of PwD, respectively. There was, however, significant heterogeneity amongst almost all effect estimates reported. The first meta-analysis found the prevalence of depression differed according to the instrument used and the continent in which the study was conducted. The second meta-analysis was unable to explain the observed heterogeneity of effect sizes. Many of the included studies in the first and second meta-analysis were rated as having a 'high risk' of bias. The impact of heterogeneity and study quality is critically explored. The thesis indicates that there is a great need within this population for interventions that are effective at reducing burden and depressive symptoms, with MABIs appearing acceptable and beneficial. However, further higher quality research is needed to improve the robustness of the evidence bases and enable a meta-analysis to thoroughly examine and quantify moderator variables.

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Firstly, I would like to thank my primary supervisor Dr Naoko Kishita for always being kind, supportive, encouraging and positive about my project. I recognize and appreciate the fact that at times you went out of your way to be available for me in order to ensure that my project was on schedule for the deadline. Thank you to my second supervisor Dr Ken Laidlaw for meeting with me, reviewing my thesis and providing some valuable advice. I would like to say thank you to my Grandpa and Nanny Jackson, my Mum, Dad and my brother Sam for supporting me financially – without this support I probably wouldn't be where I am today. I would like to thank Milo and Chester for keeping me company and bringing me warmth and comfort. Most of all, I would like to say a special thank you to my mum – my best friend and my rock. You have supported me throughout my journey of aspiring to be a Clinical Psychologist and I hope that you realise how much it has meant to me. I dedicate this thesis to you.

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Chapter One: Prevalence of depression and burden among informal caregivers of people with dementia: a meta-analysis

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Prevalence of depression and burden among informal caregivers of people with dementia: a meta-analysis

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Abstract

The prevalence of depression and burden among informal caregivers of people with dementia (PwD) is unclear. This meta-analysis examined the aforementioned and compared the prevalence of depression between male and female, and spousal and non-spousal, caregivers. The quality of studies was evaluated and moderator variables explored. A comprehensive search of six electronic databases (PsycARTICLES, PsycINFO, MEDLINE Complete, SCOPUS, Web of Science and ProQuest) was conducted from the first available date to the 31st October 2017. Inclusion criteria involved observational studies that detailed the prevalence of burden or depression, assessed via self-report measures or diagnostic interviews, among informal caregivers of PwD. Forty three studies were examined with a total of 16 911 participants. The majority were conducted in Europe, followed by North America. The adjusted pooled prevalence of depression was 31.2% (95% CI 27.7% to 35.0%) and burden was 49.3% (95% CI 37.2% to 61.5%), although heterogeneity among burden and depression prevalence estimates was significantly high. Depression prevalence estimates differed according to the instrument used and continent in which the study was conducted. The odds of having depression were 1.45 times higher in female caregivers compared to male caregivers. No significant difference was observed between the prevalence of depression among spouses and non-spouses. Most studies were rated as having a medium risk of bias. The results indicate that there is a great need for interventions that are effective at reducing burden and depressive symptoms. Given the increasing economic impact of dementia, and the negative influence these difficulties can have on a caregiver's ability to perform their role, it would appear imperative for dementia services that are not currently providing such interventions to do so.

Introduction

Dementia is a syndrome caused by a progressive brain disease that deteriorates memory, thinking, behaviour and the ability to perform everyday activities (World Health Organization; WHO, 2017a). The number of people with dementia (PwD) is rising every year. By 2051, there will be approximately two million PwD in the United Kingdom (UK), under the assumptions that there are no public health interventions and these changes are driven by an ageing population alone (Alzheimer's Society, 2018). Dementia has therefore been perceived as one of the greatest problems facing society in the twenty-first century (Alzheimer's Society, 2014).

In the late 1980's, the UK's perception of dementia began to alter; moving away from classifying PwD as 'senile' and providing hospital-based care, to the use of formal diagnostic procedures and providing care within a community-based framework (Brooker, 2017). Today, the majority of PwD are community-dwelling and are primarily cared for by a spouse or an adult child, typically of the female gender (Alzheimer's Research UK, 2015). The increasing number of dementia cases means that the number of informal caregivers (unpaid relatives or friends) of PwD is also increasing. Research indicates that informal caregivers of PwD can experience positive benefits from the acquisition of the caregiving role, such as feeling as though family members have come closer together and appraising life as more fulfilling and meaningful (Cohen, Colantonio & Vernich, 2002). However, there is an abundance of literature that suggests that the role can lead to the presence of perceived burden (e.g. Chiao, Wu & Hsaio, 2015; Brodaty & Donkin, 2009) and psychological difficulties. In particular, there is a strong evidence base for the presence of depressive symptoms, that are significantly higher compared to older

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adults who are not caregivers (Vitaliano, 1997) and caregivers of people without dementia (Pinquart & Sörensen, 2003), and anxiety symptoms; of which the prevalence has been reported elsewhere (Kaddour & Kishita, 2018).

Burden

It is acknowledged that there are ethical issues and concerns from patient groups around the use of the term ‘burden’, with many perceiving this term to mean that the person with dementia is a ‘burden’. However the concept of burden in this review corresponds to a known literature and is conceptualised as a multidimensional biopsychosocial reaction (Given, Given, Azzouz, Kozachik, & Stommel, 2001) resulting from the caregiver’s perception of numerous aspects of the caregiving situation. It is the caregiver’s perception of the degree to which the care-recipient is dependent upon them as well as how the caregiving role has had a negative impact upon their emotional health, physical health and social or financial status (Zarit, Todd & Zarit, 1986). Literature has frequently attempted to make a distinction between ‘objective’ and ‘subjective’ burden, although this distinction still remains unclear. Thompson and Doll (1982) suggested that ‘objective burden’ was related to the disruption to family life and ‘subjective burden’ to the caregiver’s response to the situation. The current burden definition is based on that of Zarit, Todd and Zarit (1986) which has been suggested to include ‘objective burden’ concepts (e.g. physical, social and financial impacts and level of dependency) and ‘subjective burden’ concepts (e.g. the caregiver’s perceptions and the emotional impact of caregiving), and is in line with most of the well-established and validated caregiver burden measures (Vitaliano, Young & Russo, 1991).

When taking into account this burden definition and the research comparing the experiences of caregivers of people with and without dementia, it becomes clear why caregivers of PwD might perceive greater burden. Caregivers of PwD tend to spend more hours per week on caregiving tasks, assist with a greater number of activities of daily living, report more employment complications and less time for leisure and social activities due to caregiving responsibilities (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999), and spend more of their own money on caregiving expenses (O'Brien, 2016). Interestingly, the higher the caregiver burden experienced by caregivers of PwD, the more likely they are to expedite nursing home placement (Gaugler, Kane, Kane & Newcomer, 2005).

Observational studies and reviews of caregiver burden in caregivers of PwD have tended to focus on the relationships between burden and psychological constructs such as depression, and predictors of burden. These have revealed that depressive symptoms and caregiver burden are positively correlated with one another (Epstein-Lubow, Davis, Miller & Tremont, 2008; Medrano, Rosario, Payano & Capellan, 2014) and there are significant patient related predictors of burden such as the patients' severity of dementia, behavioural problems or psychological symptoms and extent of personality change, and caregiver related predictors of burden including sociodemographic variables and psychological health (Etters, Goodall & Harrison, 2008; Chiao, Wu & Hsaio, 2015). These studies have therefore been significant in uncovering the potential difficulties that may be experienced by those with perceived burden and the types of factors that increase a caregiver's vulnerability to experiencing perceived burden. However to our knowledge there has been no meta-analytic review of the prevalence of burden among informal caregivers of PwD. Determining the global prevalence of burden among this population would

appear vital to further our psychological understanding of this population and help inform the provision of services.

Depression

Depressive symptoms include a persistent sadness/low mood, marked loss of interest or pleasure in activities, disturbed sleep, decreased or increased appetite or weight, loss of energy, poor concentration, feelings of worthlessness or guilt and/or suicidal ideation or acts (American Psychiatric Association; APA, 2013). To fulfil the DSM-V criteria for major depression at least one of the first two symptoms must be present alongside five of the remaining symptoms nearly every day for at least two weeks (APA, 2013). There are numerous self-report measures that have been designed to map onto the diagnostic criteria for depression, include specified cut-offs to determine depression, and have been validated in older adult populations. The most frequently used measure in research on caregivers of PwD is the Centre for Epidemiological Studies-Depression (CES-D; Radloff, 1977).

Depression is the leading cause of disability worldwide (WHO, 2017b). Caregivers who have depression typically experience problems in daily functioning and have poorer physical health (Gallagher, Rose, Rivera, Lovett & Thompson, 1989; Cucciare, Gray, Azar, Jimenez & Gallagher-Thompson, 2010). Moreover, a large cross-sectional study of 566 informal caregivers of PwD revealed that approximately 16% had contemplated suicide more than once in the previous year (O'Dwyer, Moyle, Zimmer-Gembeck & De Leo, 2016). Although a smaller longitudinal study found the prevalence of suicidal thoughts to be substantially lower than this at 4.7% (Joling, O'Dwyer, Hertogh, & van Hout, 2018), both studies reported depression to be a risk factor for suicidal ideation. Therefore, in regards to the care of the person with dementia, at least depression can compromise a

caregivers' ability to effectively maintain their role and at worst it can lead to suicide; demonstrating why investigating the prevalence of depression among this population is important.

A meta-analysis conducted 13 years ago estimated the pooled prevalence of depressive disorders among informal caregivers of PwD, assessed via interviews based on the DSM-III(-R)/IV (APA, 1980; APA, 1987; APA, 1994) or ICD-10 (WHO, 1992). This was found to be approximately five times higher than that of the general population, at 22.5% (Cuijpers, 2005). A more recent meta-analysis by Sallim, Sayampanathan, Cuttilan and Ho (2015) estimated the pooled prevalence of depression among caregivers of people with Alzheimer's disease (AD), measured via self-report instruments, to be 34%. However, both reviews included a small number of studies.

A contextual model (Fig 1.) by Williams (2005) adapted from that of Dilworth-Anderson and Anderson (1994) conceptualised the factors that may influence the likelihood of a caregiver of someone with dementia experiencing depression; scoring above a specified cut off on a self-report measure e.g. ≤ 16 on the CES-D. Among other factors, gender (within 'sociocultural context') and the relationship to the care-recipient (within 'temporal context') were posited to influence this likelihood.

Indeed, one meta-analysis found the prevalence of depression to be higher in female caregivers of people with AD compared to male caregivers of people with AD, and higher in spousal caregivers of people with AD compared to non-spousal caregivers of people with AD (Sallim et al., 2015). However, this review was limited to caregivers of people with AD and, due to the extremely small number of included studies in each meta-analysis ($n = 3$) and the lack of assessment of publication bias,

findings may not be robust. It is important to note that using meta-analytic approaches to investigate the influence of the other contextual factors presented in the adapted model of Williams (2005) on depression would not be appropriate, given that research often presents these factors as summary data (e.g. the percentage of the sample that are married) and conducting moderator analyses on such data would introduce aggregation bias (Harbord, 2010).

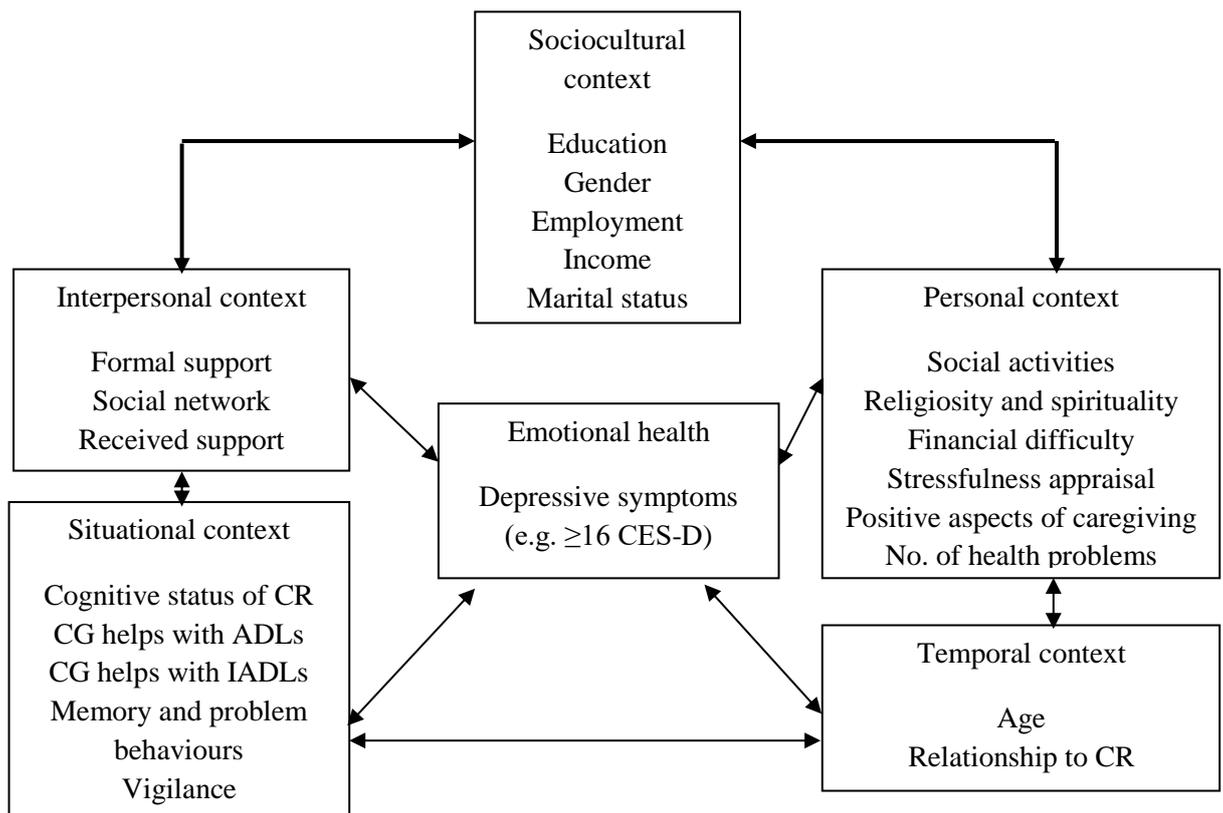


Fig 1. The conceptual model for understanding the effects of context on emotional health outcomes among caregivers of people with dementia, adapted from the model of Dilworth-Anderson and Anderson (1994). CES-D = Center for Epidemiological Studies–Depression Scale; CR = care recipient; CG = caregiver; ADLs = activities of daily living; IADLs = instrumental ADLs.

Determining the current prevalence of burden and depression is necessary to estimate the need for services and the requirement to develop, adapt, or change the availability of, specific treatments to fulfil the needs of this client group, and so help delay and reduce rates of transition into care homes (Alzheimer’s disease

International, 2013; Gaugler et al., 2005). The study aimed to address the gaps in the literature on burden and depression in caregivers of PwD by conducting a current comprehensive meta-analysis with the following objectives:

- (1) To quantify the prevalence of caregiver burden among informal caregivers of PwD, including studies with well-established and validated self-report measures for informal caregivers of PwD that are in line with the burden definition.
- (2) To quantify the prevalence of depression among informal caregivers of PwD, assessed via diagnostic measures or validated self-report measures.
- (3) To compare the prevalence of depression among female and male caregivers and spousal and non-spousal caregivers.
- (4) To explore moderator variables including the methodological quality

Method

The meta-analysis adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Moher et al., 2009).

Eligibility Criteria

Articles were included if they were written in English or Japanese and used observational study designs (see Munn, Moona, Lisy & Riitano, 2014) including prospective and retrospective longitudinal cohort studies, case-control studies, cross-sectional studies and studies that analysed baseline data from other studies of randomized controlled trials (RCTs). All other study designs were excluded, such as experimental or quasi-experimental studies, qualitative studies, and review articles.

The population studied were informal caregivers of PwD. Studies involving caregivers of people without dementia or professional caregivers (e.g. paid support

workers) were excluded. There were no limitations on the gender or age of the caregivers, the dementia type of the care-recipients, the setting or time spent as a caregiver. Studies were included if they sought to recruit a representative sample of its population. Studies were therefore excluded if they recruited *only* caregivers with specific mental or physical health difficulties, such as those experiencing insomnia or depressive symptoms or they actively excluded caregivers experiencing a current depressive episode.

Similar to the meta-analyses of Krebber et al. (2014) and Wang et al. (2017), studies were included if they reported the number or percentage of individuals with depression assessed by semi-structured or structured diagnostic interviews based on criteria by DSM-III(-R)/IV or ICD-10, or validated self-report measures with specified clinical cut-offs. Studies were included if they reported the number or percentage of caregivers that scored above a specified cut-off for burden on a burden measure that had evidence of high internal consistency, validity, and being an effective tool for assessing burden in caregivers of PwD. For instance, the Caregiver Burden Inventory (CBI; Novak and Guest, 1989) and the most widely referenced burden measure, The Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980). Studies not reporting depression or burden prevalence data were excluded.

Initially, articles published in any year were included. However, during the screening of full text articles the authors decided that only studies published from the year 2000 onwards were eligible for inclusion. This decision was made because a number of factors have changed substantially from prior to the year 2000 to the present day which could have impacted upon the accuracy of the current prevalence estimates of depression and burden. UK older adult services in the late 1980's rarely diagnosed dementia, it was common for PwD to be hospitalised, and there was a lack

of psychologically informed care (Brooker, 2017). In contrast, from around the 1990's there has been an increase in the formal diagnosis of dementia and a shift towards community based care, with most PwD today living in the community and receiving care from a relative or friend (Schulz & Martire, 2004). The evidence base for and provision of psychosocial and psychological interventions (e.g. Cognitive Simulation Therapy; Spector et al., 2003) has also grown. Other factors taken into account included life-style changes and technological advances, the increase in the prevalence of depression in the general population (WHO, 2017b), and the reduction in stigma towards depression in the last 20 years (Taylor Nelson Sofres British Market Research Bureau Limited, 2014) - potentially increasing the likelihood of caregivers disclosing depressive symptoms.

Information sources

A comprehensive search of the literature was conducted. The databases of PsycARTICLES, PsycINFO, MEDLINE Complete, SCOPUS and Web of Science were searched to identify relevant published articles. Unpublished articles including dissertations and theses were sought through the ProQuest global database. Hand searches were performed on the reference lists of included studies and relevant prevalence reviews and meta-analyses obtained via The Cochrane Online Library.

Search

The first author performed the search using the keywords and search strategies outlined in Table 1. All databases were searched from their inception to 31st October 2017 and no limits were applied to language.

Table 1. Search strategy and key terms

Concepts	Search terms
Epidemiology ¹	'epidemiologic' OR 'epidemiological' OR 'epidemiol*' OR 'prev*' OR 'inciden*'
Burden/depression ²	'depress*' OR 'depression emotion' OR 'distress' OR 'depressive disorder' OR 'major depression' OR 'burden'
Type of participants ³	'Dementia' OR 'Alzheimer's' OR 'cognitively impaired' OR 'caregiver' OR 'carer' OR 'care' OR 'caring' OR 'caregiving' OR 'family caregiver' OR 'family carer' OR 'informal caregiver' OR 'informal carer'
Combined	1 2 AND 3

Note: For the databases PsycARTICLES, PsycINFO and MEDLINE Complete the key words in the 'epidemiology concept' were searched for in the abstracts of texts and the 'burden/depression' and 'participants' concepts in the title of texts. The SCOPUS search was limited to articles, reviews and conference papers, and all key words were searched for in the titles and abstracts of articles. The key words were searched for in the titles of texts within the Web of Science database and abstracts of texts within the Proquest database.

Study selection

The results of the searches were merged using EndNote software (version X8.0) and duplicate articles removed. Eligibility assessment was conducted in a non-blinded manner. The first author performed the initial screening of the titles and abstracts, whereby clearly irrelevant articles were excluded. The full text articles were screened by both authors independently using a structured checklist created by the

first author (Appendix C). The kappa coefficient was 0.68 indicating substantial agreement (Cohen, 1960). Disagreements between reviewers were resolved through discussions. When data from studies overlapped, the report with the largest sample size or data set was included.

Data collection process

The first author developed an electronic database which was pilot tested on a randomly-selected study by both authors collaboratively and refined accordingly. In order to reduce errors and minimise bias, both authors independently extracted the data from 11 of the included studies (10%) and results were compared, with no significant discrepancies identified. Data extraction was completed on the remaining studies by the first author independently and the data transferred to the Comprehensive Meta-Analysis software (CMA version 3; Borenstein, Hedges, Higgins, & Rothstein, 2005).

Data items

Information was extracted from each study based on (1) characteristics of the study (including year of publication, country, design, recruitment process, sample size and instruments used to assess depression and/or burden); (2) characteristics of the caregivers (including the definition given for a caregiver, mean age, percentage female, race, nationalities, average length of time spent caregiving in months, percentage employed, percentage married, mean years of education and types and percentages of relationships held with the care-recipients); (3) characteristics of the care-recipients (including procedure used to diagnose dementia, percentages of the types of dementia diagnoses and severity of dementia - primarily measured by a mean MMSE score); (4) depression and burden outcome data (including the number

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or percentage of participants within the sample that were diagnosed with depression or scored above the specified clinical cut-off, and the number or percentage of females and males, and spouses and non-spouses that were diagnosed with depression or scored above the specified cut-offs). Information was not inputted if it was missing or unclear and not made available by study authors.

Risk of bias in individual studies

The bias risk of each study was investigated using a 13-item list adapted from existing criteria lists (Krebber et al., 2014; Luppá et al., 2012). Adaptations were made with regards to the population being studied and focused on: (i) the description of the caregivers including information about the care-recipients' diagnosis and (ii) the representativeness of this population. Items for the description of the caregivers included sociodemographic characteristics (age and gender, and at least one of the following four: marital status, education, employment or socioeconomic status), inclusion and exclusion criteria, dementia diagnostic procedure, dementia diagnoses and severity, time spent as a caregiver, inclusion and exclusion criteria and information about (a history) of psychiatric problems of the caregivers. Items of the representativeness of the study population included sample size >100, description of participation or response rate and this being at least 75%, reasons for nonresponse/nonparticipation presented or a statistical comparison of the characteristics of responders and non-responders, description of the recruitment process and use of a consecutive sampling method. A risk item was given a score of one if the study provided adequate information. If the information was incomplete or unclear, a zero score was given. If a study referred to another publication describing relevant information about the first study (e.g. recruitment process), the additional publication was obtained to score the item of concern. For each study, a total bias

score was calculated by summing the 'one' scores. A study was considered of low bias risk if the score was at least 75% of the total (≥ 9.75), of medium bias risk if it was between 50–75% of the total (6.5–9.75) and high risk if below 50% of the total (≤ 6.5).

The risk assessment tool was pilot tested on a randomly selected study by both authors collaboratively and refined accordingly. Subsequently, the authors independently rated eleven randomly-selected studies and compared the results. There were a few discrepancies between the ratings. If a risk item was rated positively by one author but not the other, a discussion was held and often the conservative value was chosen. The remaining studies were assessed by the first author independently.

Summary measures

Meta-analyses were conducted by computing the event rate of depression and burden using CMA (Borenstein et al., 2005). This calculates the number of 'events' (people reaching the threshold for perceived burden or depression) divided by the total number of events (total sample size).

Synthesis of results

Effect sizes (event rates), their 95% confidence intervals (CIs) and associated z and p values were computed using the number of caregivers who scored above the specified cut-offs for depression or burden and sample size. As considerable heterogeneity of event rates was expected, the pooled prevalence estimate and its 95% CI were calculated using a random-effects model. To assess for heterogeneity among studies, the chi squared statistic (Q ; Higgins & Thompson, 2002) and I squared statistic (I^2 ; Higgins, Thompson, Deeks & Altman, 2003) were computed. I^2 provides

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a percentage of the total observed variability in effect estimates due to heterogeneity rather than chance and is not affected by low statistical power. An I^2 of 25% is considered low, 50% moderate and 75% high.

Risk of bias across studies

Publication bias was assessed by constructing funnel plots of the logit event rate by the logit event rate standard error (SE). The logit event rate is calculated using the formula:

$$\text{Log} (\text{event rate}/1-\text{event rate})$$

The logit event rate SE is calculated using the formula:

$$\text{Square root} (1/ (\text{event rate} \times \text{total}) + 1/ ((1- \text{event rate}) \times \text{total}))$$

The trim and fill method was also calculated (Duval & Tweedie, 2000a). This estimates how many studies could be missing from each meta-analysis, corrects the funnel plot symmetry, and calculates adjusted effect size estimates.

Additional analyses

A sensitivity analysis was conducted to determine whether the burden pooled prevalence estimate would have differed substantially if a study that measured ‘persisting’ burden (Epstein-Lubow, Davis, Miller & Tremont, 2008) was omitted. As samples enrolled in RCTs could differ from samples who are not, a random-effects sub-group analysis was performed to determine whether prevalence estimates differed according to whether studies used a cross-sectional sample or one taken from an RCT at baseline.

Odds ratio effect sizes, their 95% confidence intervals (CI) and associated z and p values were computed on the proportion of female caregivers compared to

male caregivers that were classed as depressed, and the proportion of spouses compared to non-spouses that were classed as depressed. Two meta-analyses using random effects models were conducted to ascertain the overall odds ratio estimates and their 95% confidence intervals.

A random-effects meta-regression investigated the relationship between study quality and the prevalence estimates of depression and burden. A random-effects sub-group analysis was also conducted to determine whether depression prevalence estimates differed according to the type of measure used to assess depression and the continent the study was conducted in.

Results

Study selection

The database searches produced 8568 articles and hand searching 35 articles, resulting in a total of 8603 studies (Fig. 2). After the removal of 1905 duplicates, 6698 titles and abstracts were reviewed, with 6584 articles deemed clearly irrelevant and excluded. The full texts of the remaining 114 articles were screened, with 71 not fulfilling criteria and 43 studies included in the meta-analysis.

One study used a higher cut off for the burden measure compared with other included studies that used the same measure, as it assessed ‘persisting burden’ rather than the presence of burden (Epstein-Lubow et al., 2008). The authors included the study and assessed its potential impact via additional analyses.

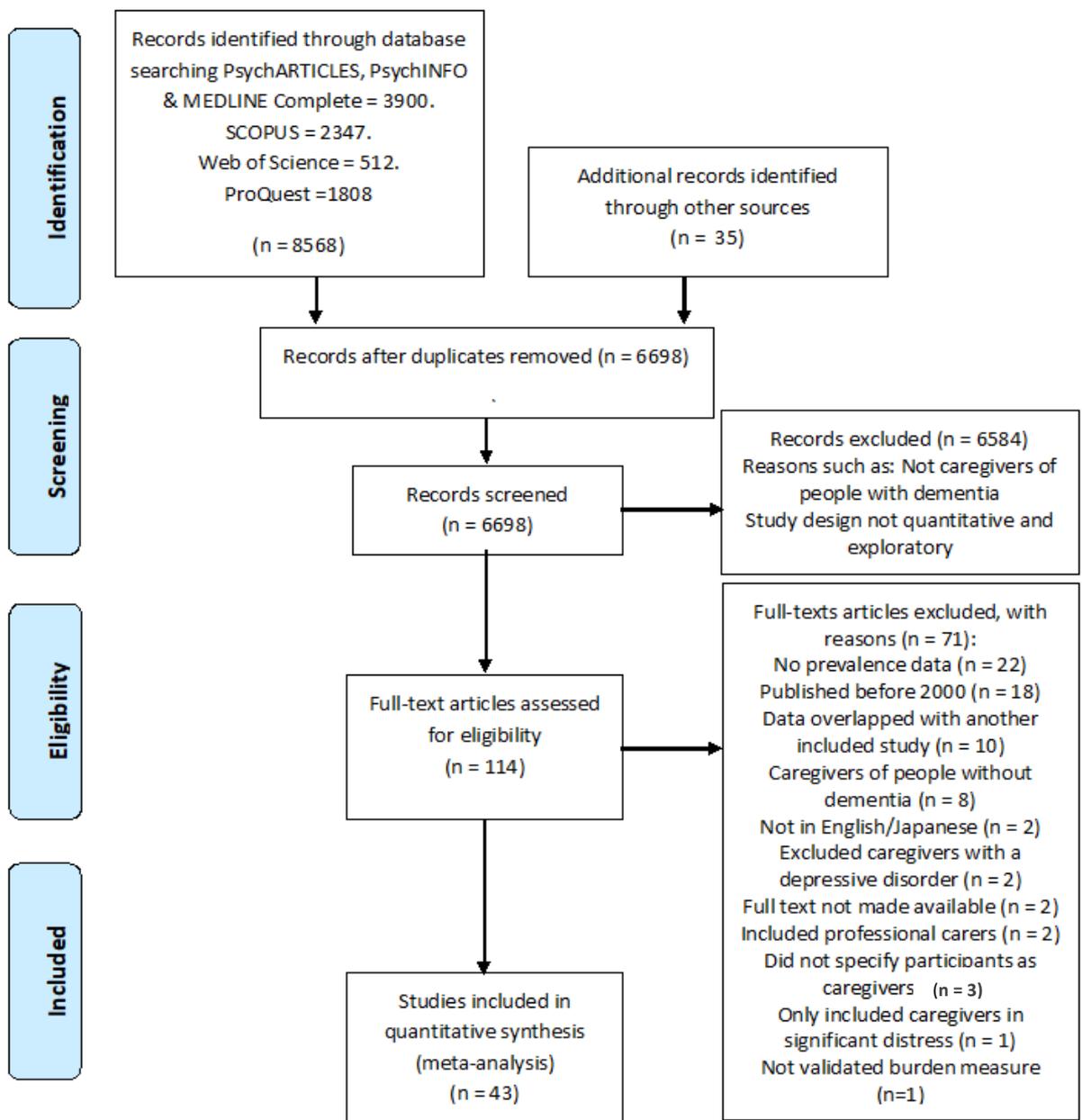


Fig.2. PRISMA flowchart of information from identification to inclusion of studies.

Study characteristics

The key characteristics of the 43 included studies are provided in Table 3D in Appendix D within the Supplementary Material. See also Appendix F within the Supplementary Material for the references of all the studies included in the meta-analysis that are not cited in the text. Twenty-one studies were published between

2012 and 2016, 11 between 2006 and 2011 and 11 between 2000 and 2005. The total number of participants included in the meta-analysis was 16 911. Most of the studies were conducted in Europe (19), followed by North America (16), Asia (3), Australia (3) and South America (2). The majority of studies used cross-sectional designs (28), with the remaining studies using baseline RCT data (8), adopting a longitudinal prospective cohort design (4), and using baseline data from longitudinal prospective cohort studies (3). The recruitment procedures varied greatly across studies. Sixteen recruited from multiple different platforms. For example, the study of Cheng, Lam and Kwok (2013) which recruited caregivers from memory clinics, outpatient clinics, day hospitals, day care centres and social services. Seventeen recruited from one database or service, and 10 recruited from two or more of the same types of service, such as several memory clinics (e.g. Brodaty et al. 2014).

Of the 40 studies that reported the proportionality of genders, all were predominantly female (ranging from 54 – 100%). Thirty-three studies reported the mean age of the sample (ranging from 51.8 to 83.5 years old). Of the 40 studies that reported the percentages of relationships between the caregivers and care-recipients, 20 had a majority of spouses and 20 a majority of non-spouses (typically adult children). Twenty-four studies reported the tools used to diagnose dementia or a form of dementia in *all* care-recipients (see Appendix G for a reference list including the diagnostic tools used); seven of these used the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA; McKhann et al., 1984) alone or in conjunction with other diagnostic tools or procedures. Twenty one studies reported the percentages of the care-recipients' dementia diagnoses. Eleven studies were 100% Alzheimer's Disease (AD), seven were primarily AD followed by varying forms of

dementia, one was 75% AD and 25% Lewy Body Dementia (LBD), one was a majority of Frontotemporal Dementia (FTD) followed by AD then other dementias, and one was 100% FTD.

Twenty-six studies reported the dementia severity of care-recipients as a mean (15), percentages (8), both (2), or a median (1). The majority used the Mini Mental State Exam (MMSE; Folstein, Folstein & McHugh, 1975) and/or the Clinical Dementia Rating Scale (CDRS, Hughes, Berg, Danziger, Coben, & Martin, 1982). The percentage of caregivers employed was reported in 11 studies (ranging from 17 to 54.6%). The percentage of caregivers married was reported in eight studies (ranging from 57.4 to 87.8%). The average years of education was reported in six studies with a range of 6.6 to 14.1.

Structured diagnostic interviews were used in two of the 38 studies that reported the prevalence of depression; leaving 36 studies that used self-report depression measures (Table 3D). The 20-item CES D (Radloff, 1977) with cut-off ≥ 16 was used the most times (11) to measure depression. Of the nine studies that reported the prevalence of burden, eight used a version of the 22-item Zarit Burden Interview (ZBI; Zarit, Reever & Bach-Peterson, 1980). See Appendix G for a reference list including all of the measures used.

Risk of bias within studies

The mean bias score was 7 (SD = 1.65), and scores ranged from 4 (highest risk bias) to 11 (lowest risk) (Fig. 3a). Of the 43 studies assessed, 18 had a high risk, 22 had a medium risk and three a low risk.

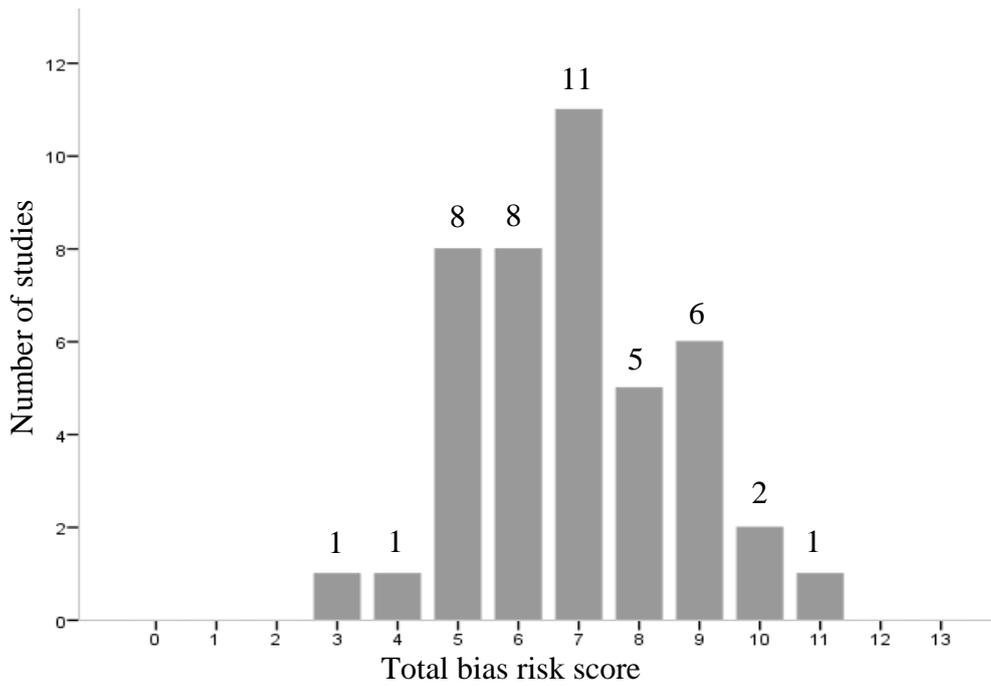


Fig. 3a. Bias risk assessment of 43 studies: number of studies per rating

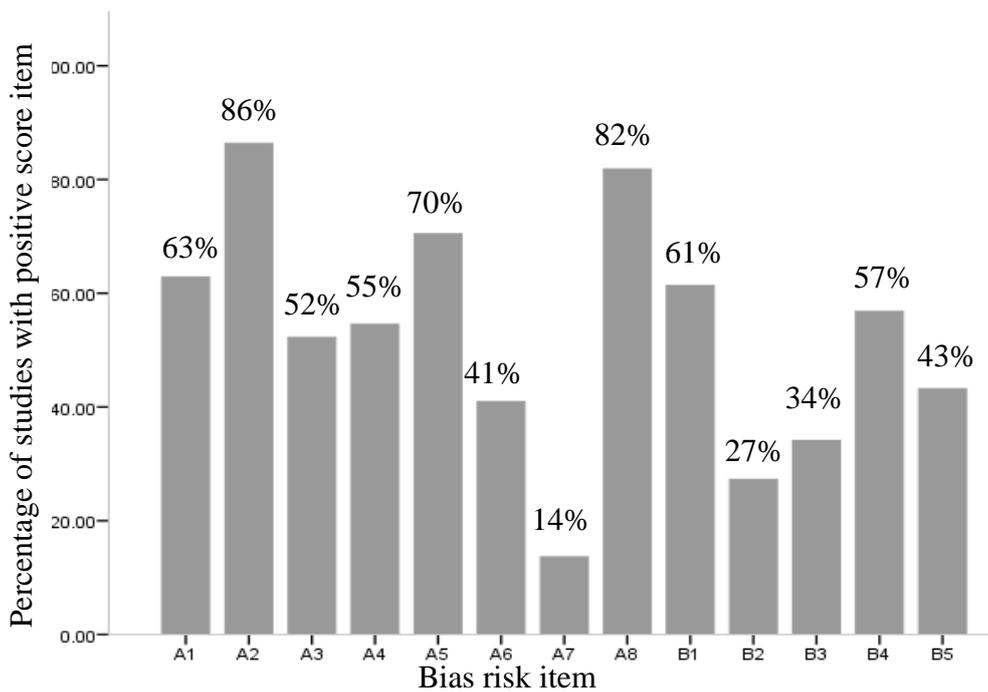


Fig. 3b. The percentage of studies with a positive score on each risk item.

As can be seen in Fig. 3b, over 80% of the studies reported the percentages of the types of relationships between caregivers and care-recipients, and inclusion and exclusion criteria. More than half had a sample size ≥ 100 and reported sufficient socio-demographic information, the dementia diagnostic procedure, percentages of

dementia diagnoses, dementia severity, and provided an adequate description of the recruitment method. The most underreported risk items were ‘(history of) psychiatric problems’ (14%) and ‘participation and response rates are described and are more than 75%’ (27%). See Figures 3a and 3b for a full description of the risk bias assessment results.

Results of individual studies

Fig. 4 and Fig.5 show forest plots of prevalence estimates for burden and depression, including their 95% confidence intervals (CI) and associated z and p values.

Synthesis of results

Prevalence of depression

Thirty-eight studies included prevalence estimates of depression. These ranged from 3% to 57%; although it must be noted that the study with a 3% prevalence estimate (Lowery et al., 2000) had the highest standard error and could be considered an outlier (Copas & Shi, 2000). Overall, prevalence estimates of depression yielded a pooled prevalence of 33.6% (95% CI 29.9% to 37.5% $p < .001$). However, the heterogeneity of the prevalence estimates was significantly high ($I^2 = 94.0\%$, $Q = 612.3$, $p < .001$).

Prevalence of burden

Nine studies reported prevalence estimates of burden; estimates ranged from 35.8% to 88.5%, with a pooled prevalence of 62.1% (95% CI 51.2% to 72.0% $p = .031$). However, heterogeneity was significantly high among prevalence estimates ($I^2 = 94.9\%$, $Q = 157$, $p < .001$).

Prevalence of depression and burden among caregivers of people with dementia

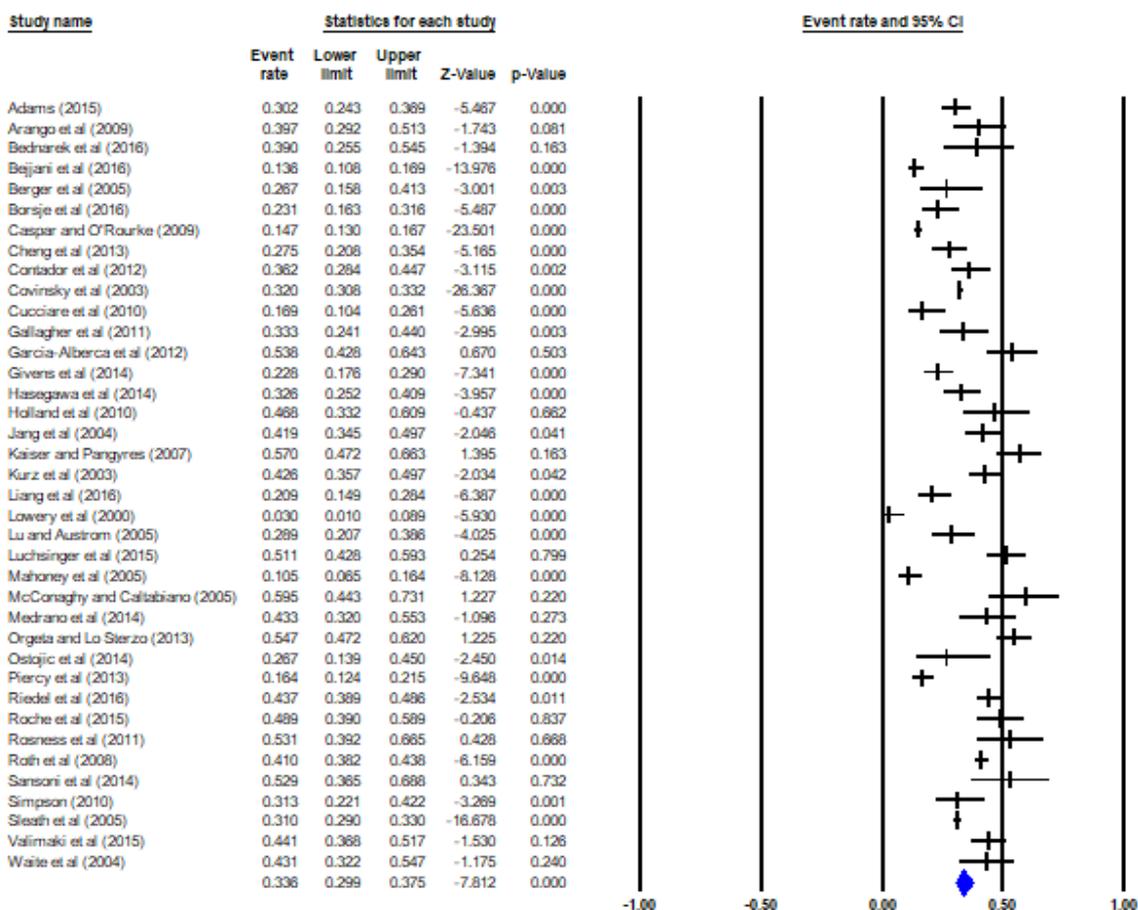


Fig 4. Forest plot on the prevalence of depression among caregivers of people with dementia.

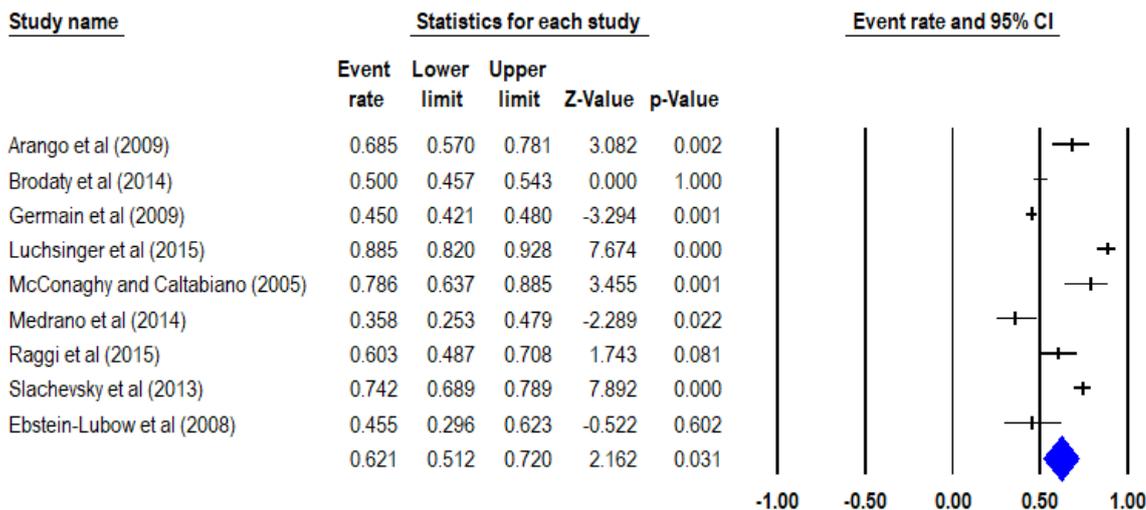


Fig 5. Forest plot on the prevalence of burden among caregivers of people with dementia.

Risk of bias across studies

Studies on depression

The trim and fill method indicated four potentially missing studies that would need to fall on the left side of the pooled prevalence estimate to make the plot symmetrical (Fig 6.). Assuming a random-effects model, the new pooled prevalence estimate reduced to 31.2% (95% CI 27.7% to 35.0%).

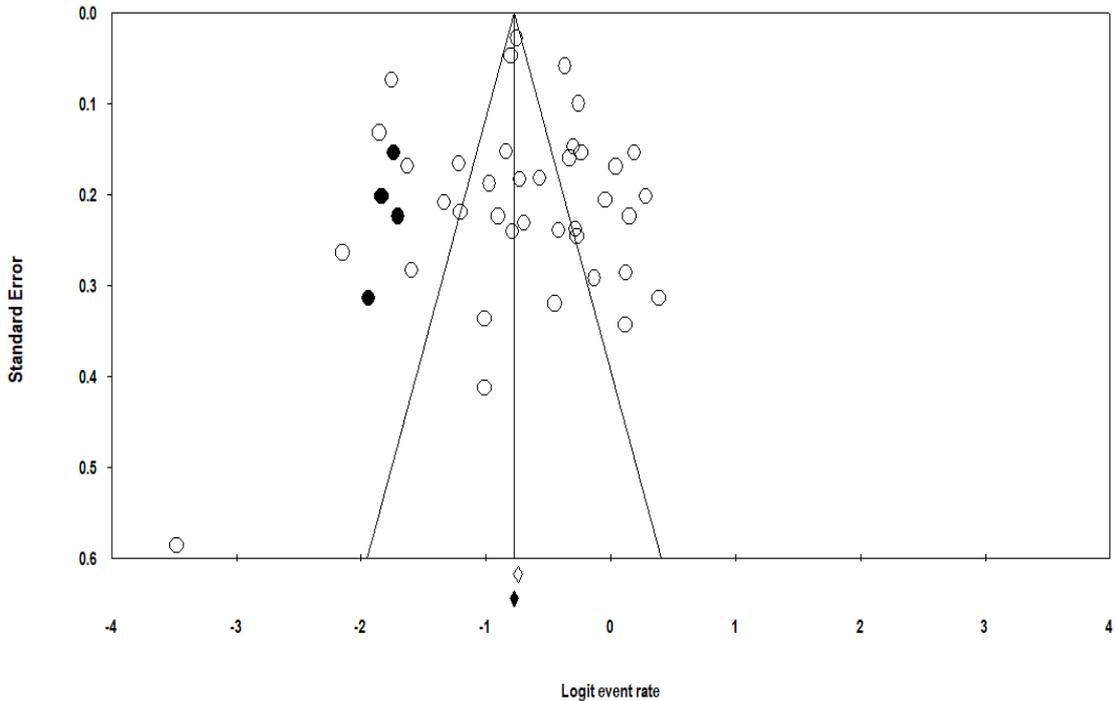


Fig 6. Random effects funnel plot of logit event rate depression effect sizes by standard error

Studies on burden

The trim and fill method indicated three potentially missing studies that would need to fall on the left side of the pooled prevalence estimate to make the plot symmetrical (Fig 7.). Assuming a random-effects model, the new pooled prevalence estimate reduced to 49.3% (95% CI 37.2% to 61.5%).

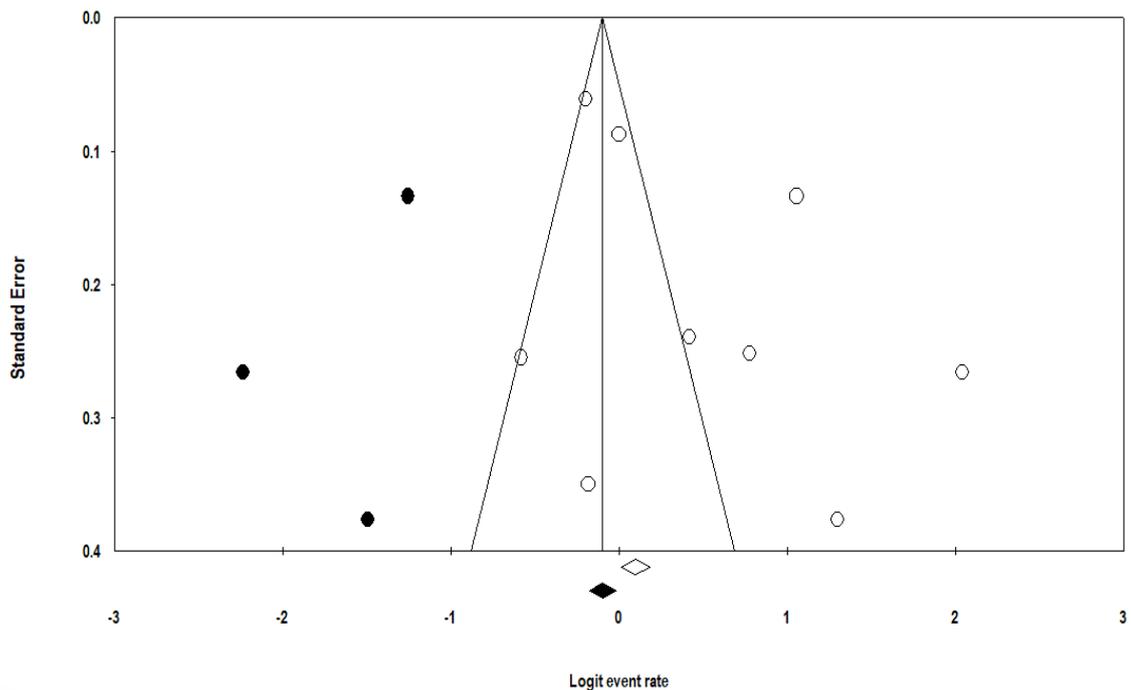


Fig 7. Random effects funnel plot of logit event rate burden effect sizes by standard error.

Additional analyses

Sensitivity analysis

Following the omission of Epstein-Lubow et al. (2008) the prevalence of burden increased by a minimal percentage (1.4%). The analysis found no deviations from the main analysis in terms of the heterogeneity of prevalence estimates or significance of the pooled prevalence.

Subgroup analysis

Random-effects sub group analysis comparing RCT data to non-RCT data was not appropriate for burden outcomes, given that only one of the nine studies used baseline RCT data (Epstein-Lubow et al., 2008). The depression pooled prevalence estimate of studies that used baseline RCT data did not significantly differ to that of studies where samples were obtained via cross-sectional or longitudinal prospective cohort designs ($p = .734$). The second random-effects sub-

group analysis included thirty-two studies and revealed that depression prevalence estimates differed according to the type of measure used ($p = .003$); two studies that used diagnostic criteria reported the lowest prevalence rate (8.9%, 95% CI 3.4% to 21.4%, $I^2 = 88.0\%$), although one of these studies may be considered an outlier, followed by studies that used a form of the Hospital Anxiety and Depression Scale (HADS; 26%, 95% CI 15.6% to 40.1%, $I^2 = 95.9\%$). Five studies that used a form of the Beck Depression Inventory (BDI) reported the highest prevalence estimate (49.2%, CI 34.3% to 64.2%, $I^2 = 59.7\%$). As there were no studies conducted in Africa and only one study based in South America reporting depression prevalence data, the random-effects sub-group analysis for continent compared the pooled prevalence estimates of Asia, Europe, Australia and North America. There was a significant difference between the depression pooled prevalence estimates of the continents entered into the analysis ($p < .0007$), with Asia reporting the lowest estimate of 26.8% (CI 17.2% to 39.2%), followed by North America 29.1% (CI 24.3% to 34.6%), Europe 36.8% (CI 31.1% to 42.8%) and Australia yielding the highest estimate of 58.1% (CI 40.0% to 74.3%).

Meta-regression results

Study quality was not a significant moderator of depression prevalence estimates (0.0254, 95% CI -0.0816 to 0.1324, $p = .641$) or burden prevalence estimates (-0.18, 95% CI 0.144 to -0.461, $p = .215$).

Odds-ratio meta-analyses

The first meta-analysis included eight studies (Fig 8.) and revealed that the odds of a female caregiver having depression was 1.45 times higher than a male caregiver (95% CI 1.125 to 1.874, $p = .004$). There was no significant heterogeneity of the odds ratio estimates. The trim and fill method indicated no missing studies

from the analysis (see Fig 9E in Appendix E within the Supplementary Material.).

The second meta-analysis included seven studies and the odds of a spouse compared to a non-spouse having depression was found to be 1.15, however this was not significant (95% CI 0.737 to 1.779, $I^2 = 84.4$, $p = .547$). The trim and fill method suggested there were no missing studies from this analysis.

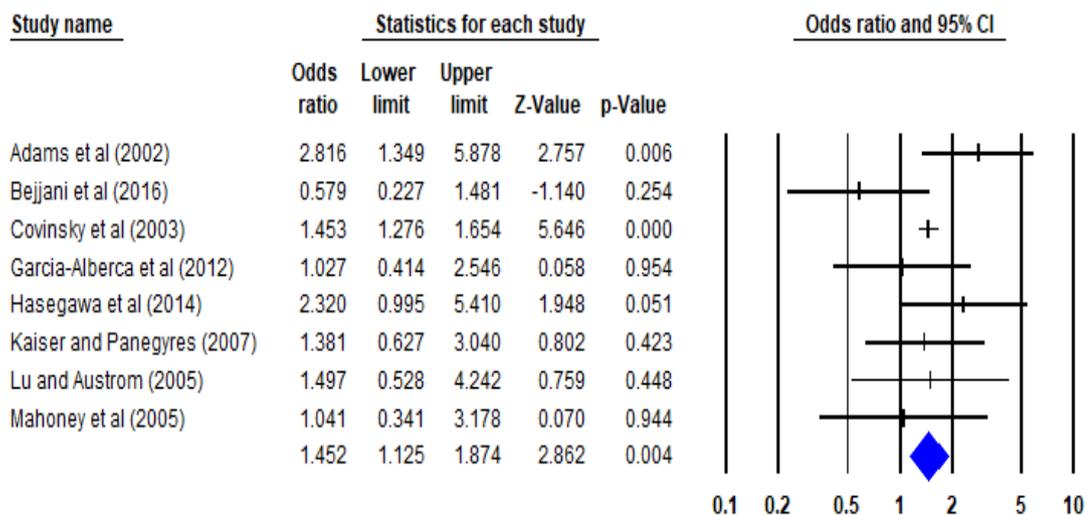


Fig 8. Forest plot on gender of caregiver and its impact on the prevalence of depression

Discussion

Forty-three studies set across five of the seven continents, predominantly comprising of cross-sectional designs, were examined with a combined total of 16 911 participants of diverse ages and relational statuses to care-recipients. To our knowledge, this was the first meta-analysis to quantify the prevalence of perceived burden among informal caregivers of PwD. Overall the trim-and-fill adjusted prevalence estimate of burden was 49.3%. In other words, approximately half of all the informal caregivers of PwD perceived their caregiving role to be burdensome. There does not appear to be any meta-analytic reviews into the prevalence of burden among other types of caregivers; however, given the substantial differences found between the experiences of carers for people with and without dementia (Ory,

Hoffman, Yee, Tennstedt & Schulz, 1999; O'Brien, 2016), it is likely that this prevalence is greater. There may be numerous reasons for why the remaining half of the population perceived their role to have little to no burden. This could include that these caregivers perceived more positive benefits from the acquisition of the caregiving role. For example, if a caregiver perceives that their family has become closer together, this could impact upon their response to questions regarding the social impact of the role - a construct of caregiver burden. Importantly, the finding highlights a great need within this population for interventions effective at reducing perceived burden. Such interventions could increase the wellbeing of caregivers during their role, which could prolong the transition of care-recipients to care homes, and prevent post-death psychiatric morbidity (Gaugler et al., 2005).

The trim-and-fill adjusted prevalence estimate of depression was 31.2%, suggesting that at this present time almost a third of all caregivers of PwD are experiencing depression. The depression prevalence estimate is substantially higher than that of the prevalence of depression among adult primary care patients, assessed via structured diagnostic interviews (Mitchell, Vaze & Rao, 2009) and the prevalence of depression in older adult populations, assessed via self-report measures (Li, Zhang, Shao, Qi & Tian, 2014; Luppá et al., 2012). It is also higher than that of the prevalence of depression among caregivers for people with cancer (Krebber et al., 2014), but lower than that reported for caregivers of stroke survivors (Loh et al., 2017). Given that depression has been found to be a risk factor for suicidal ideation among family caregivers of PwD, the high prevalence of depression supports the finding of higher prevalence rates of suicidal ideation in this population compared to the general population (O'Dwyer et al, 2013; O'Dwyer et al., 2016). Overall, the finding demonstrates that more informal caregivers of PwD are in need

of interventions to reduce depressive symptoms than the adult/older adult general population; in line with the indications of previous observational studies (e.g. Pinguart & Sörensen, 2003).

Interestingly the depression prevalence estimate was higher than that found in the study of Cuijpers (2005). This could be attributed to the fact that all of the studies within Cuijpers (2005) were conducted at least 12 years ago and therefore its estimate may not reflect the current prevalence in today's population. The difference could also be due to the fact that all studies in Cuijpers (2005) were based in either the UK or the USA, unlike the current review which included depression prevalence estimates from studies conducted in numerous countries across Europe, multiple states in North America, and several places in Asia and Australia. In addition to this, the current review included almost four times as many studies and so may have provided a more accurate prevalence estimate. Finally, the review of Cuijpers (2005) only included studies that assessed depression via semi-structured or structured diagnostic interviews, whereas the current meta-analysis also included studies that assessed depression via self-report measures. It has been reported that, compared with self-report measures, interview methods commonly underestimate the prevalence of psychiatric disorders (Mitchell et al., 2011). In line with this and the findings of other meta-analytic reviews (e.g. Krebber et al, 2014), the current review discovered that the depression prevalence estimates differed according to the instrument used to assess depression, with interviews based on diagnostic criteria yielding the lowest pooled prevalence estimate. This could also explain why the overall depression prevalence estimate was similar to that found in Sallim et al. (2015) where studies were included if they assessed depression via self-report measures or structured diagnostic interviews.

The review also found that female caregivers are 1.45 times more likely to experience depression than male caregivers; although further observational studies comparing the prevalence of depression between male and female caregivers of PwD are warranted. No significant difference in terms of depression prevalence was observed between spousal and non-spousal caregivers; indicating that caregivers who are adult children, friends or other relatives of the care-recipient may be just as much at risk of developing depression as caregivers who are spouses of the care-recipient. This outcome did not support the finding of Sallim et al. (2015), where spousal caregivers of patients with AD were 2.51 times more likely than non-spousal caregivers of patients with AD to experience depression. It is not thought that this is attributed to the fact that the current study included caregivers of people with all forms of dementia, but because the current review included over twice as many studies; three of which reported a higher prevalence of depression in non-spousal caregivers compared to spousal caregivers.

Limitations

Although study quality was not found to be a significant moderator of the burden or depression prevalence estimates, 18 studies were rated as having a high risk of bias and only three studies rated as having a low risk of bias. The majority of studies failed to report any details of the history of psychiatric problems for the informal caregivers. Most did not report details of the participation and response rates or when these were reported they were less than 75%, and most studies did not compare those that did respond/participate to those that did not (either qualitatively or quantitatively). This could mean that within these studies a large proportion of caregivers did not respond/participate. If this were true, this could have affected the accuracy of the burden prevalence estimate particularly given that one of the reasons

some informal caregivers of PwD do not engage with services is due to a high level of burden (Brodaty, Thompson and Fine, 2005).

Other limitations of the current review include the findings of significantly high heterogeneity of depression and burden prevalence estimates which suggests that these estimates are not similar across studies and conclusions drawn are limited by this fact. Interestingly, the purpose of recruitment did not appear to impact the prevalence estimates as the pooled prevalence of studies that used baseline RCT data did not significantly differ to that obtained for studies using cross-sectional designs and longitudinal prospective cohort designs. The heterogeneity among depression prevalence estimates was however partially explained by the type of instruments used to measure depression, with studies using diagnostic criteria yielding the lowest pooled prevalence estimate. In terms of self-report measures, studies that used a form of the HADS yielded the lowest pooled prevalence estimate and studies using a form of the BDI had the highest pooled prevalence estimate. These findings reflect those of a recent meta-analysis of the prevalence of depression among medical outpatients (Wang et al., 2017). The self-report measures are designed to assess clinically significant depressive symptoms but they are not tools for diagnosing different types of mood disorders; for example, the HADS does not include all of the diagnostic criteria for depression based on DSM (Laidlaw, 2015). It is therefore perhaps unsurprising that the two studies that used diagnostic criteria reported the lowest prevalence rate. Moreover, the HADS was designed to detect depression and anxiety in people with medical conditions, and thus it is useful for older people with chronic physical illnesses. Although the BDI is a well-established measure, it can be criticised for having somatic scale items as this may inflate scores when used with older people (Laidlaw, 2015). Considering that many informal caregivers of PwD are

older people, this may account for the significantly large difference observed between the pooled prevalence estimates of studies that used the HADS and the BDI. It is also acknowledged that different cut-offs may have affected the diagnostic sensitivity and specificity.

The study also revealed that prevalence estimates differed by continent. Asia appeared to have the lowest prevalence of depression, followed by North America, Europe and Australia, respectively. Unfortunately the review could not include South America within the sub-group analysis as only one study conducted in this region reported the prevalence of depression, and overall no included study was conducted in Africa. This leaves a question as to whether the prevalence of depression among informal caregivers of PwD differs greatly in these continents.

A final limitation of the review is that it does not shed light on which aspects of depression or burden caregiver's perceive as most severe. For example, in terms of burden, caregiver's may find that their physical health has suffered the most as a result of the role. It may be helpful for future research to explore whether certain symptoms of depression and aspects of burden are rated as more severe than others in this population in order for services to establish and tailor the most effective interventions.

Conclusion and future directions

This review revealed that almost one third of informal caregivers of PwD experience depression and approximately one half appraise their caregiving role to be burdensome. Unfortunately, significant heterogeneity of depression and burden prevalence estimates was observed. As reported in other reviews, different screening instruments were found to produce different estimates of depression. The heterogeneity of depression prevalence estimates was also partially explained by the

continent the studies were conducted in; with Asia reporting the lowest pooled prevalence and Australia the highest. The review indicates that female caregivers are more at risk of experiencing depression than male caregivers. However, further observational studies investigating this finding are warranted. No significant difference in terms of depression prevalence was observed between spousal and non-spousal caregivers. Overall, this review demonstrates that within this population there is a great need for the provision of interventions that are effective at reducing burden and depressive symptoms. Informal caregivers of PwD save international governments billions of pounds every year (Brodaty & Donkin, 2009). Given that these difficulties can negatively impact upon a caregiver's health, ability to perform their role (Gallagher et al., 1989; Cucciare et al, 2010), and increase the likelihood of the care-recipient being transitioned to a nursing home placement (Gaugler et al., 2005), economically, it would appear vital for dementia services that are not currently providing interventions that are effective at reducing these difficulties to do so.

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Supplementary Material

Appendix A

Psychology and Aging author guidelines

Submission

To submit to the Editorial Office of Elizabeth A. L. Stine-Morrow, please submit manuscripts electronically through the Manuscript Submission Portal in Word Document format (.doc).

Submit manuscript:

Elizabeth A. L. Stine-Morrow

University of Illinois at Urbana–Champaign

General correspondence may be directed to the [Editor's Office](#)

In addition to addresses and phone numbers, please supply email addresses and fax numbers, if available, for potential use by the editorial office and later by the production office.

Psychology and Aging[®] is now using a software system to screen submitted content for similarity with other published content. The system compares the initial version of each submitted manuscript against a database of 40+ million scholarly documents, as well as content appearing on the open web. This allows APA to check submissions for potential overlap with material previously published in scholarly journals (e.g., lifted or republished material).

Masked Review Policy

Masked reviews are optional, and authors who wish masked reviews must specifically request them at submission. Authors requesting masked review should

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make every effort to see that the manuscript itself contains no clues to their identities.

Authors' names, affiliations, and contact information should be included only in the cover letter.

If your manuscript was mask reviewed, please ensure that the final version for production includes a byline and full author note for typesetting.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).

Review APA's [Checklist for Manuscript Submission](#) before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.

Additional guidance on APA Style is available on the [APA Style website](#).

Length

Articles

Articles do not typically exceed 8,000 words, excluding references, tables, and figures. Shorter manuscripts are equally welcome.

Articles exceeding the 8,000 word limit may be considered if they offer an especially novel theoretical framework, or complex methodology or statistical approach that requires more extensive exposition.

Brief Reports

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The Brief Report format is reserved for particularly "crisp," theoretically noteworthy contributions that meet the highest methodological standards.

Brief reports are typically no longer than 3,500 words, excluding references, tables, and figures, and include no more than two tables or figures.

Papers in this format differ in length from regular articles, but not in rigor.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Title Page

The first manuscript page is a title page, which includes a title of no more than 12 words, the author byline and institutional affiliation(s) where the work was conducted, a running head with a maximum of 50 characters (including spaces), and the author note.

Abstract and Keywords

All manuscripts must include an abstract typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

For regular articles, abstracts are no longer than 250 words; for brief reports, no longer than 100 words.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Examples of basic reference formats:

Journal Article:

Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin, 139*, 133–151.

<http://dx.doi.org/10.1037/a0028566>

Authored Book:

Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach*. Cambridge, MA: MIT Press.

Chapter in an Edited Book:

Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, [please see the general guidelines](#).

When possible, please place symbol legends below the figure instead of to the side.

APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.

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The same caption will appear on both the online (color) and print (black and white) versions. To ensure that the figure can be understood in both formats, authors should add alternative wording (e.g., "the red (dark gray) bars represent") as needed.

For authors who prefer their figures to be published in color both in print and online, original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay:

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An additional \$600 for the second figure

An additional \$450 for each subsequent figure

Additional instructions for equations, computer code, and tables follow:

Display Equations

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

To construct your equations with MathType or Equation Editor 3.0:

Go to the Text section of the Insert tab and select Object.

Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation.

Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

Computer Code

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material

We request that runnable source code be included as supplemental material to the article. For more information, visit [Supplementing Your Article With Online Material](#).

In the Text of the Article

If you would like to include code in the text of your published manuscript, please submit a separate file with your code exactly as you want it to appear, using Courier New font with a type size of 8 points. We will make an image of each segment of code in your article that exceeds 40 characters in length. (Shorter snippets of code that appear in text will be typeset in Courier New and run in with the rest of the text.)

Prevalence of depression and burden among caregivers of people with dementia

If an appendix contains a mix of code and explanatory text, please submit a file that contains the entire appendix, with the code keyed in 8-point Courier New.

Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

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In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

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You may also request a copy by [emailing](#) or calling the APA Ethics Office (202-336-

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5930). You may also read "Ethical Principles," December 1992, *American Psychologist*, Vol. 47, pp. 1597–1611.

Supplementary Material

Appendix B

Email communication from Psychology and Aging

Dear Miss Collins,

Your submission "Prevalence of depression and burden among informal caregivers of people with dementia: a meta-analysis" has been assigned the following manuscript number: PAG-2018-0026.

You will be able to check on the progress of your paper by logging on to Editorial Manager as an author. The URL is <https://age.editorialmanager.com/>.

Thank you for considering Psychology and Aging as an outlet for your work.

Best regards,

Psychology and Aging

Supplementary Material

Appendix C

Study eligibility criteria checklist

Study Characteristics	Eligibility criteria <i>(Insert inclusion criteria for each characteristic as defined in the Protocol)</i>	Eligibility criteria met?			Location in text or source <i>(pg & //fig/table/other)</i>	
		Yes	No	Unclear		
Type of study	Prospective and retrospective cohort study			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Case control study			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Cross sectional study	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Explorative (not an intervention study, review, conference paper, psychometric properties of an instrument)			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Client group	Informal (familial, unpaid, non-professional) caregivers of someone with dementia (alive)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Inclusion criteria of participants	Study included depressed subjects (did not only include these individuals or excluded them)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Validated self-report depression measure or diagnostic criteria as assessed with a psychiatric or standardized diagnostic interview	HADS (Hospital Anxiety and Depression Scale)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	CES-D (Centre for Epidemiologic Studies – Depression Scale)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	BDI I or II (Beck Depression Inventory)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	Another validated self-report measure:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	DSM; RDC; ICD using DISC, CIDI, or SCAN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Prevalence	The number or percentage of the sample that fulfilled the clinical cut off or diagnostic criteria of depression is stated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	The number or percentage of sample that scored at a particular level on the burden measure is stated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Study language	English	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	Japanese	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Depression	Major Depressive Disorder (i.e. not Bipolar etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

Prevalence of depression and burden among caregivers of people with dementia

defined as

'Increased risk of depression'

Validated self-report of burden

Eg. Zarit Burden Inventory:

INCLUDE (Yes to all answers)

EXCLUDE (no to at least 1 answer)

Reason for exclusion

Prevalence of depression and burden among caregivers of people with dementia

Borsje et al. (2016)	Netherlands ; Southern regions	Longitudinal prospective cohort	General Practitioner surgeries	ICPC-2	N/A	117	67.3	68.4%
Brodaty et al. (2014)	Australia; multiple locations	Longitudinal prospective cohort	Three memory clinics	DSM-IV criteria for dementia	AD 71.2% VD 7% FTD 4.2% Mixed dementia 17.6%	524	N/A	64.9%
Caspar and O'Rourke (2009)	Canada; all provinces except Ontario	Cross-sectional	Government health records	MMSE, neurological and neuropsychological assessment	N/A	1426	N/A	N/A
Cheng et al. (2013)	China, Hong Kong	Cross-sectional	Memory clinics, outpatient clinics, day hospitals, day care centres and social services	NINCDS-ADRDA criteria for AD	AD 100%	142	58.9	73%
Contador et al. (2012)	Spain; Salamanca	Cross-sectional	Referrals to the Association of Family Members of Patients with Alzheimer's	DSM-IV-R for dementia	AD 40.8% VD 28.4% Mixed dementia 30.8%	130	58.6	72%

Prevalence of depression and burden among caregivers of people with dementia

Covinsky et al. (2003)	USA; MN, FL, OR, NY, TN, OH and IL	Baseline RCT data	Physician referrals and self-referrals	N/A	N/A	5627	64	71.7%
Cucciare et al (2010)	USA; CA	Baseline RCT data	Health and social services professionals, media, and word of mouth	Physician diagnosis or MMSE below 23	N/A	89	51.8	100%
Epstein-Lubow et al. (2008)	USA, New England	Baseline RCT data	Memory clinics, support groups and media	DSM-IV for dementia and Clinical Dementia Rating of mild or moderate	N/A	33	N/A	79%
Gallagher et al (2011)	Ireland, Dublin	Cross-sectional	A memory clinic	DSM-IV-R, NINCDS-ADRDA, neuropsychological and neurological assessment	AD 100%	84	63.3	57.1%
García-Alberca et al (2012)	Spain, Malaga	Cross-sectional	Local health services and the voluntary sector	NINCDS-ADRDA criteria for AD	AD 100%	80	62.2	77.5%

Prevalence of depression and burden among caregivers of people with dementia

Germain et al. (2009)	Belgium, Denmark, France, UK, Germany, Greece, Italy, The Netherlands, Romania, Spain, Sweden, Switzerland	Cross sectional using data from a longitudinal prospective cohort study	29 specialist outpatient clinics	NINCDS-ADRDA criteria for AD	AD 100%	1091	62.3	63.5%
Givens et al. (2014)	USA; MN, OR, PA	Cross sectional using a longitudinal prospective cohort study	“Population based listings”	None caregiver self-report	N/A	206	82.4	100%
Hasegawa et al. (2014)	Japan; Kumamoto city on the island of Kyushu	Cross-sectional	Two memory clinics	Neurological and neuropsychological assessments and DSM-III-R for dementia.	AD 62.2% VD 16.3% LBD 14.1% Other dementia 7.4%	135	N/A	68.2%
Holland et al. (2010)	USA; San Francisco Bay CA	Cross-sectional	Media, and professional and non-professional referrals	MMSE \leq 23 or documented diagnosis	N/A	47	59.5	100%

Prevalence of depression and burden among caregivers of people with dementia

Jang et al. (2004)	USA; NY	Baseline RCT data	Alzheimer's Disease centre, adult day care services, social services, and media	N/A	N/A	160	NS	61.5%
Kaiser and Panegyres (2007)	Australia; Perth	Cross-sectional	Neuroscience assessment and care clinic	NINCDS-ADRDA criteria for AD, consensus criteria for FTD and PPA	FTD 42% AD 36% Primary Progressive Aphasia 6% Other dementia 16%	100	62.3	54%
Kurz et al. (2003)	Belgium, multiple locations	Cross-sectional	General practitioners, specialists and psychologists.	CAMDEX and diagnosed in line with DSM-III-R	N/A	188	N/A	66.7%
Liang et al. (2016)	China; Shanghai	Cross-sectional	A memory clinic	Neuropsychological assessments and DSM-IV criteria for dementia	N/A	139	N/A	N/A
Lowery et al. (2000)	UK, Tyneside and Birmingham	Cross-sectional	Two dementia case register cohorts	Consensus criteria for DLB and NINCDS-ADRDA for probable AD	25% LBD 75% AD	100	83.5	68%

Prevalence of depression and burden among caregivers of people with dementia

Lu and Austrom (2005)	USA; OH	Cross-sectional	University Alzheimer Disease Center Caregiver Registry	N/A	N/A	97	N/A	73.2%
Luchsinger et al. (2015)	USA, NY	Baseline RCT data	Memory clinics, physicians, health fairs and talks, support groups and media	Documented diagnosis; unknown procedure	N/A	139	59.3	N/A
Mahoney et al. (2005)	UK; London and South-East regions	Cross-sectional	Local psychiatric services, the voluntary sector, nursing and residential homes	NINCDS-ADRDA criteria for AD and DSM-IV	AD 100%	153	64	69.9%
McConaghy and Caltabiano (2005)	Australia, North Queensland	Cross-sectional	Homecare dementia services	MMSE and other methods N/A	N/A	42	62	76.2%
Medrano et al. (2014)	Dominican Republic; multiple locations	Cross-sectional	A health database of over 1500 patients	NINCDS-ADRDA criteria for AD	AD 100%	67	61	84%

Prevalence of depression and burden among caregivers of people with dementia

Orgeta and Lo Sterzo (2013)	UK; multiple locations	Cross-sectional	Local voluntary sectors supporting caregivers of PwD	N/A.	N/A	170	62.4	81.2%
Ostojic et al. (2014)	Croatia, Zagreb	Cross-sectional	Psychiatric hospital	DSM-IV criteria for AD	AD 100%	30	57.7	73.3%
Piercy et al. (2013)	USA; UT	Cross sectional using data from a longitudinal prospective cohort study	N/A	N/A	AD 60% VD 14% other dementia 16%	256	67.5	76%
Raggi et al. (2015)	Italy; Sicily	Cross-sectional	Outpatients in community	DSM-5 criteria for AD, medical history, neurological and neuropsychological assessments	AD 100%	73	N/A	N/A
Riedel et al. (2016)	Germany; multiple locations	Cross-sectional	Referrals from office-based neurologists	MMSE	AD 100%	403	62.1	69%

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Roche et al. (2015)	Germany; multiple locations	Cross- sectional	Caregiver support groups, German Alzheimer's Association, and German FTD consortium	Medical diagnosis; procedure unknown	FTD 100%	94	59.1	72.3%
Rosness et al. (2011)	Norway; Oslo	Cross- sectional	A memory clinic	ICD-10 criteria for early onset dementia, physical and neurological assessments	AD 77.6% FTD 14.3% VD 6.1% LBD 2%	49	60.3	69.4%
Roth et al. (2008)	USA; AL MA, TN, FL, CA and PA.	Baseline RCT data	Multiple community sites and health social agency settings	Medical diagnosis of probable AD or related dementia (unknown procedure) or MMSE < 24	N/A	1183	62.2	81.5%
Sansoni et al. (2014)	Italy; Rome, Florence and Genoa	Cross- sectional	Three ambulatory care clinics	N/A	N/A	34	59.2	100%
Simpson (2010)	USA; TX	Cross- sectional	Flyers distributed by a geriatric psychiatric service, support groups, respite care and outreach	N/A	AD 71.3% VD 11.3% LBD/FTD 7.5% Mixed 1.3% Alcohol induced 1.3% Unknown	80	63.3	88.8%

Prevalence of depression and burden among caregivers of people with dementia

			educational programmes		7.5%			
Slachevsky et al. (2013)	Chile; primarily Santiago	Cross-sectional	Referrals from primary care centres, neurological consultations and support groups.	N/A	N/A	291	60.1	75.3%
Sleath et al. (2005)	USA; multiple locations and Puerto Rico	Cross-sectional	A national database	ICD-9 criteria for AD or VD	N/A	2032	68.1	100%
Valimaki et al. (2015)	Finland; three locations unnamed	Longitudinal prospective cohort	Three hospitals	NINCDS-ADRDA criteria for AD and DSM-IV	AD 100%	170	65.7	66.5%
Waite et al. (2004)	UK; London	Cross-sectional	Referrals from two old age psychiatry services and two dementia care centres	DSM-IV criteria for dementia and a MMSE score of < 24	AD 100%	72	80	80%

Prevalence of burden and depression among caregivers of people with dementia

Table 2D continued: Characteristics of included studies (N = 43)

Study	Relationship	Depression measure	Cut-off	Depression prevalence %	Burden measure	Cut-off	Burden prevalence %	Quality score (risk)
Adams et al. (2002)	Spouse 100%	OAHMQ	>11	30.2%	N/A	N/A	N/A	5 (high)
Arango et al. (2009)	Spouse 54.8% Child 41.1% Other relative 4.1%	PHQ-9	>5	39.7%	ZBI-22 item	≥21	68.5%	5 (high)
Bednarek et al. (2016)	Spouse 43.9% Child 29.3% Other relative 26.8%	CES-D	≥16	39%	N/A	N/A	N/A	6 (high)
Bejjani et al. (2016)	Unknown	CES-D	≥16	13.6%	N/A	N/A	N/A	5 (high)

Prevalence of depression and burden among caregivers of people with dementia

Berger et al. (2005)	Spouse 69% Child 27 % Other 4%	BDI & GDS 15-item	>10 ≥5	26.3%	N/A	N/A	N/A	7 (medium)
Borsje et al. (2016)	Spouse 65 % Child 29.1% Other 5.9%	CES-D	≥16	23.1%	N/A	N/A	N/A	8 (medium)
Brodaty et al. (2014)	Spouse 71.2% Child 21.7 % Other 7.1%	N/A	N/A	N/A	ZBI-22 item	≥21	50%	8 (medium)
Caspar and O'Rourke (2009)	N/A	CES-D	≥16	14.7%	N/A	N/A	N/A	5 (high)
Cheng et al. (2013)	Spouse 32% Child 59% Other relative 8%	HRSD	>6	27.5%	N/A	N/A	N/A	9 (medium)

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Contador et al. (2012)	Spouse 28.5% Child 51.5% Other relative 20%	GADS	>2	36.2%	N/A	N/A	N/A	11 (low)
Covinsky et al. (2003)	Spouse 50.5% Child 36.7% Other 12.9%	GDS 15-item	≥6	32%	N/A	N/A	N/A	7 (medium)
Cucciare et al (2010)	Spouse 23.5% Daughter, daughter-in-law and granddaughter 76.5%	Interview, SCID-I for DSM-IV	N/A	16.9%	N/A	N/A	N/A	7 (medium)
Epstein-Lubow et al. (2008)	Spouse 61% Child 39%	N/A	N/A	N/A	ZBI-22 item	≥29	45.5%	6 (high)
Gallagher et al (2011)	Spouse 64.3% No other details specified	CES-D-10	≥10	33.3%	N/A	N/A	N/A	6 (high)

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García-Alberca et al (2012)	Spouse 38.8% Child 43.8% Sibling 7.4% Other relative 10%	BDI Spanish version	>20	53.7%	N/A	N/A	N/A	8 (medium)
Germain et al. (2009)	Spouse 52.2% Child 36.7% Friend 2.00% Other 9.1%	N/A	N/A	N/A	ZBI-22item	≥21	45%	9 (medium)
Givens et al. (2014)	Spouse 63.6% No other details specified	CES-D	≥16	22.8%	N/A	N/A	N/A	5 (high)
Hasegawa et al. (2014)	Spouse 37% Child 48% Other 15%	CES-D	≥16	32.6%	N/A	N/A	N/A	7 (medium)
Holland et al. (2010)	Spouse 39% Daughters 54% Daughter-in-law 7%	CES-D	≥16	46.8%	N/A	N/A	N/A	9 (medium)

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Jang et al. (2004)	Spouse 100%	GDS	>11	41.9%	N/A	N/A	N/A	9 (medium)
Kaiser and Panegyres (2007)	Spouse 100%	BDI	>10	57%	N/A	N/A	N/A	7 (medium)
Kurz et al. (2003)	Spouse 53.6% Child 26.6% Sibling 3.9% Other 15.8%	BDI-short form	≥ 5	42.6%	N/A	N/A	N/A	6 (high)
Liang et al. (2016)	N/A	HADS Chinese version	≥ 8	20.9%	N/A	N/A	N/A	6 (high)
Lowery et al. (2000)	Spouse 44% Child 40% Other relative 16%	MADRS, interview and RDC criteria	N/A	3%	N/A	N/A	N/A	5 (high)

Prevalence of depression and burden among caregivers of people with dementia

Lu and Austrom (2005)	Spouse 75.3% Child 19.6% Daughter-in-law 3.1% Other 2%	CES-D	≥ 16	28.9%	N/A	N/A	N/A	6 (high)
Luchsinger et al. (2015)	Spouse 38.8% Child 56.8% Other 4.3%	GDS	≥ 10	51.1%	ZBI-22 item	≥ 21	88.5%	8 (medium)
Mahoney et al. (2005)	Spouse 44.4% Child 44.4% Friends 4.6% Other relative 6.6%	HADS	≥ 11	10.5%	N/A	N/A	N/A	9 (medium)
McConaghy and Caltabiano (2005)	Spouse 54.8% Child 35.7% Friends 2.4% Other relative 7.1%	CES-D	≥ 16	59.5%	ZBI-22 item	≥ 21	78.6%	7 (medium)
Medrano et al. (2014)	Spouse 15% Child 55% Grandchild 12% Brother 9% Other relative 9%	HRSD Spanish Version	> 8	43.3%	ZBI-22 item Spanish version	≥ 46	35.8%	7 (medium)

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Orgeta and Lo Sterzo (2013)	Spouse 52.6% Child 29.3% Other relative 18.1%	HADS	≥ 8	54.7%	N/A	N/A	N/A	6 (high)
Ostojic et al. (2014)	Spouse 26.7% Child 63.3%	HADS Croatian translation	≥ 11	26.7%	N/A	N/A	N/A	5 (high)
Piercy et al. (2013)	Spouse 45% Child 50% Other 5%	BDI-II	≥ 14	16.4%	N/A	N/A	N/A	8 (medium)
Raggi et al. (2015)	Spouse 57.5% Child 38.4% Sibling 2.7% Nephew 1.4%	N/A	N/A	N/A	CBI	>24	60.3%	5 (high)
Riedel et al. (2016)	Spouse 48.5% Child 36.3% Son-in-law/daughter-in-law 5.5% Other 9.4%	DSQ	≥ 10	43.7%	N/A	N/A	N/A	10 (low)

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Roche et al. (2015)	Spouse 79.8% no other details specified	BDI-II	≥ 13	48.9%	N/A	N/A	N/A	4 (high)
Rosness et al. (2011)	Spouse 100%	GDS-15 item	≥ 5	53.1%	N/A	N/A	N/A	7 (medium)
Roth et al. (2008)	Spouse 48.2% Child 41.8% Other 10.1%	CES-D	≥ 16	41%	N/A	N/A	N/A	7 (medium)
Sansoni et al. (2014)	Spouse 73.53% Sister 1.94% Daughter 11.76% Friend 2.94% Other relative 8.82%	GDS	> 15	52.9%	N/A	N/A	N/A	6 (high)
Simpson (2010)	Spouse 50.1% Child 41.3% Sibling 2.5% Other 6.3%	CES-D	≥ 16	31.3%	N/A	N/A	N/A	10 (low)

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Slachevsky et al. (2013)	Spouse 40% Child 43% Sibling 5% Relative in law 4% Friends 1%	N/A	N/A	N/A	ZBI-22 item Chilean version	>46	74.2%	8 (medium)
Sleath et al. (2005)	Spouse 92% Sister and daughter 8%	CES-D modified version	≥ 9	31%	N/A	N/A	N/A	9 (medium)
Valimaki et al. (2015)	Spouse 70.24% Non-spouse 29.76%	BDI	>10	44.1%	N/A	N/A	N/A	7 (medium)
Waite et al. (2004)	Spouse 45.8% Daughters 31.9% Friends or other relatives 22.5%	GDS-15 item	≥ 5	43.1%	N/A	N/A	N/A	6 (high)

Table 2D continued: Characteristics of included studies (N = 43)

Study	Dementia severity	Percentage employed %	Percentage married %	Years of education (mean)
Adams et al. (2002)	N/A	N/A	N/A	N/A
Arango et al. (2009)	N/A	27.4%	76.7%	9.3
Bednarek et al. (2016)	GDS: 80% presented as severe to very severe (VI and VII)	N/A	78%	N/A
Bejjani et al. (2016)	N/A	N/A	N/A	N/A
Berger et al. (2005)	GDS: stage III 44% stage IV 29% stage V 18% stage VI 9%	40%	N/A	N/A
Borsje et al. (2016)	Mean MMSE 19.5	N/A	N/A	N/A
Brodaty et al. (2014)	Mean MMSE 21.8; Mean CDRS = 0.9 (mild dementia)	N/A	N/A	N/A
Caspar and O'Rourke (2009)	N/A	N/A	N/A	N/A
Cheng et al. (2013)	CDRS: Very mild 6% mild 30% moderate 54% severe 11% very severe	31%	N/A	9.9
Contador et al. (2012)	CDRS = mild 36% moderate 33% and severe 31%	N/A	N/A	N/A
Covinsky et al. (2003)	MMSE less than 15 (severe) 46.6% 15-20 (moderate) 25.1% and greater 20 (mild) 28.3%	N/A	57.4%	N/A
Cucciare et al (2010)	N/A	N/A	61.8%	N/A
Epstein-Lubow et al. (2008)	N/A	N/A	N/A	N/A
Gallagher et al (2011)	Mean MMSE 19.2	N/A	N/A	N/A

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García-Alberca et al (2012)	Mean MMSE 15.01	N/A	78.8%	6.6
Germain et al. (2009)	Mean MMSE 20.4	36.1%	N/A	N/A
Givens et al. (2014)	N/A	N/A	N/A	N/A
Hasegawa et al. (2014)	Mean MMSE 16.8, CDRS very mild 30.4%, mild 43.7%, moderate 21.5% and severe 4.4%.	N/A	N/A	N/A
Holland et al. (2010)	MMSE mean 12.2	N/A	N/A	13.1
Jang et al. (2004)	N/A	N/A	N/A	N/A
Kaiser and Panegyres (2007)	N/A	25%	N/A	N/A
Kurz et al. (2003)	MMSE: mild 28.51% mild to moderate 37.68% moderate 15.94% severe 17.87%	N/A	N/A	N/A
Liang et al. (2016)	N/A	N/A	N/A	N/A
Lowery et al. (2000)	Mean MMSE 12.7, CDRS ranged from 1-3 with a mean of 1.7 (mild-moderate)	N/A	N/A	N/A
Lu and Austrom (2005)	N/A	20.6%	N/A	N/A
Luchsinger et al. (2015)	IQCDE mean 75.79 (maximum 80 = severe)	N/A	N/A	N/A
Mahoney et al. (2005)	MMSE: 28.8% mildly impaired 41.1% moderately impaired 30.1% severely impaired	32.7%	79.8%	N/A

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McConaghy and Caltabiano (2005)	MMSE mean 17.3	17%	N/A	N/A
Medrano et al. (2014)	N/A	N/A	60%	N/A
Orgeta and Lo Sterzo (2013)	N/A	N/A	76.3	N/A
Ostojic et al. (2014)	N/A	N/A	N/A	N/A
Piercy et al. (2013)	N/A	N/A	N/A	14.2
Raggi et al. (2015)	Median MMSE 16	54.6%	N/A	N/A
Riedel et al. (2016)	Mean MMSE 17.8	31.5%	N/A	N/A
Roche et al. (2015)	N/A	N/A	N/A	N/A
Rosness et al. (2011)	Mean MMSE 21.5 for AD caregivers and 23.5 for FTD caregivers	51%	87.8%	N/A
Roth et al. (2008)	Mean MMSE 12.56	N/A	N/A	13.1
Sansoni et al. (2014)	Mean MMSE 12.38	35.2%	88.2%	N/A
Simpson (2010)	CDRS mean 25.4	41.3%	N/A	15.5
Slachevsky et al. (2013)	All GDS > 3	N/A	N/A	7.2
Sleath et al. (2005)	N/A	N/A	N/A	N/A
Valimaki et al. (2015)	CDRS between 0.5 (very mild) 54.7% and 1 (mild) 45.3%	N/A	N/A	9.9
Waite et al. (2004)	Mean MMSE 14, CDRS 29.2% mild dementia, 43% moderate dementia, 27.8% severe dementia	N/A	N/A	N/A

Note: N/A = not available. Location: AL = Alabama; CA = California; FL = Florida; IL = Illinois; MA = Massachusetts; MN = Minnesota; NY = New York; OH = Ohio; OK = Oklahoma; OR = Oregon; PA = Pennsylvania; RI = Rhode Island; TN = Tennessee;

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TX = Texas; UK = United Kingdom; USA = United States of America; UT = Utah. Design: RCT = Randomized Controlled Trial. Recruitment source: USC = University of Southern California. Dementia diagnostic tools: CAMDEX = Cambridge Mental Disorders of the Elderly Examination (Roth et al., 1986); DSM-III-R/IV/IV-R/5 = Diagnostic and Statistical Manual of Mental Disorders third edition revised (APA, 1987)/fourth edition (APA, 1994)/ fourth edition revised (APA, 2000)/fifth edition revised (APA, 2013); ICD-9/10 = International Statistical Classification of Diseases and Related Health Problems-9th Revision (WHO, 1978)/10th Revision (WHO, 1992); ICPC-2 = International Classification of Primary Care-Second Edition (WHO, 2003); MMSE = Mini Mental State Exam (Folstein, Folstein & McHugh, 1975); NINCDS-ADRDA = National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (McKhann et al., 1984). Dementia terms: AD = Alzheimer's Disease; FTD = Frontotemporal Lobe Dementia; DLB = Dementia with Lewy Bodies; PPA = Primary Progressive Aphasia; PwD = people with dementia; VD = Vascular Dementia. Depression measures: BDI-I/short form/II/Spanish Version/Chilean Version = Beck Depression Inventory (Beck et al., 1961)/short-form (Beck & Beck, 1972)/second edition (Beck, Steer, Ball & Ranieri, 1996)/Spanish Version (Conde & Useros, 1975)/Chilean Version; CES-D/-10/modified version = Centre for Epidemiological Studies-Depression (Radloff 1977)/10-item (Andresen, Malmgren, Carter, & Patrick, 1994)/modified version (Hays, Blazer & Gold, 1993); DSQ = Depression Screening Questionnaire (Wittchen, Höfler, & Meister, 2001); GADS = Goldberg Anxiety and Depression Scale (Goldberg, Bridges, Duncan-Jones, & Grayson, 1988); GDS/-15-item = Geriatric Depression Scale (Yesavage et al., 1983)/15-item (Yesavage & Sheikh, 1986); HADS original/Chinese Version = Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)/-Chinese Version (Chan, Leung, Fong, Leung, & Lee, 2010); HRSD/-Spanish version = Hamilton Rating Scale for Depression (Hamilton, 1980)/-Spanish version (Ramos-Brieva, 1986); MADRS = Montgomery Asberg Depression Rating Scale (Montgomery & Asberg, 1979); PHQ-9 = Patient Health Questionnaire-9 (Kroenke, Spitzer & Williams, 2001); OAMHQ = The Older Adult Health and Mood Questionnaire (Kemp and Adams, 1995); SCID-I = Structured Clinical Interview for DSM-IV Axis I Disorders (First, Spitzer, Gibbon, & Williams, 2008); RDC = Research Diagnostic Criteria (Spitzer & Robins, 1978). Burden measures: ZBI 22-item/Spanish version/Chilean version = Zarit Burden Interview (Zarit et al., 1980)/Spanish version (Martín et al., 1996)/Chilean Version (Breinbauer et al., 2009); CBI = Caregiver Burden Inventory (Novak & Guest, 1989). Dementia severity tools: CDRS = Clinical Dementia Rating Scale (Hughes, Berg, Danziger, Coben & Martin, 1982); GDS = Global Deterioration Scale (Reisberg, Ferris, de Leon & Crook, 1982); IQCDE = Informant Questionnaire on Cognitive Decline in the Elderly (Jorm, 2004).

Appendix E

The prevalence of depression among females compared to males

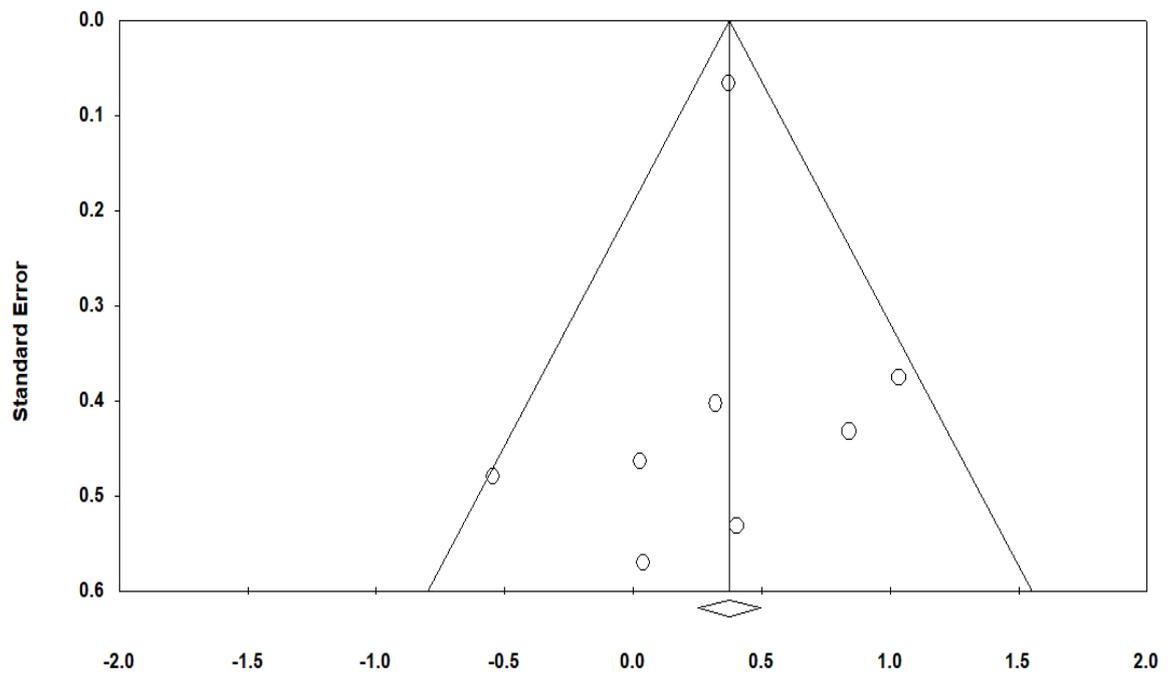


Fig 9E. Random effects funnel plot of log odds ratio male-female depression prevalence estimates by standard error.

Appendix F

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Appendix G

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Running head: bridging chapter

Chapter Two: Bridging Chapter

Word count: 854

Chapter Two: Bridging Chapter

The first meta-analysis introduced the rapidly increasing size of the dementia problem. It must be noted that dementia is an umbrella term that includes diagnoses such as Alzheimer's disease, Vascular Dementia, Mixed Dementia, Lewy Body Dementia, Frontotemporal Dementia, and other rarer forms of dementia (Alzheimer's Society, 2018). All dementia diagnoses are debilitating, progressive and currently incurable. To emphasise the economic impact of dementia further, in the UK dementia has higher health and social care costs (£11.9 billion) than cancer and chronic heart disease combined (Luengo-Fernandez, Leal & Gray, 2015) and, with the number of people living with dementia set to rise to 1.2 million by 2040, these costs are expected to double with the overall cost of dementia rising from £26 billion to £55 billion. (Prince et al., 2014). Dementia dramatically changes the lives of people who live with it, together with their families, friends and communities (Alzheimer's New Zealand, 2016). As previously outlined, informal caregivers (relatives or friends that provide practical and/or emotional support) of PwD lessen the economic impact of dementia; without such caregivers the figures quoted above would be substantially higher. One way informal caregivers lessen the economic burden of dementia is by reducing and delaying the transition of care-recipients to care homes (Alzheimer's disease International, 2013). However, the role of caring for someone with dementia can come at a cost to the caregiver; with research in this field heavily focused on the experience of 'caregiver burden' and 'depression'.

Although researchers have defined 'caregiver burden' in varying ways, the first meta-analysis conceptualised it as a biopsychosocial reaction resulting from the caregiver's perception of the level of dependency of the care-recipient, and the impact of the role on their emotional health, physical health and social life or

Bridging chapter

financial status (Given et al., 2001; Zarit et al., 1986). This definition and the measures that fall in line with it attempts to capture aspects of both ‘objective burden’ and ‘subjective burden’. It is important to note that, although the distinction between these concepts remains somewhat unclear, measures that only assess ‘objective burden’ are said to capture ‘caregiver strain’ (Robinson, 1983), whereas measures that capture both are said to measure ‘caregiver burden’ (Rombough, Howse & Bartfay, 2012). Although research had revealed the moderators of perceived burden, and the association between burden and depressive symptoms, little was known about how many caregivers of PwD perceive their role to be burdensome. This seemed vital in order to further our understanding of the struggles that this population may face and to inform the provision of services.

The first meta-analysis introduced the concept of ‘depression’ in accordance with diagnostic criteria, and clarified the importance of investigating the prevalence of depression among this population. Two previous meta-analyses had reported on this; one of which was conducted more than a decade ago (Cuijpers, 2005) and the other focused on caregivers of people with AD, used a small number of studies and lacked assessment of publication bias (Sallim et al., 2015). It therefore appeared necessary to conduct a robust and comprehensive investigation into the current prevalence of depression among this population. The first meta-analysis also referred to the adapted contextual model of Williams (2005) and argued the appropriateness of exploring the differences in the prevalence of depression between female and male caregivers and spousal and non-spousal caregivers.

Following comprehensive searches and screening methods, 43 studies were included within the review. The main findings from the first meta-analysis were that

Bridging chapter

almost half of informal caregivers of PwD perceive their role to be burdensome and almost a third experience depression, although there was significantly high heterogeneity amongst these prevalence estimates. The prevalence of depression was higher than that for the general adult population and specifically the older adult population (Li, Zhang, Shao, Qi & Tian, 2014; Luppá et al., 2012). These results were discussed in the context of the possible negative effects that these difficulties can have on a caregiver's ability to perform their role, the care of the care-recipient, and the research finding depression to be a predictor of suicidal ideation among informal caregivers of PwD (e.g. O'Dwyer et al., 2016). Overall, the review highlighted that a significant proportion of this population are in need of interventions effective at reducing depressive symptoms and burden.

As will be outlined in the second meta-analysis, the NICE (2006) guidelines recommend psychological therapy, including cognitive-behavioural therapy, for informal caregivers of PwD who experience psychological distress and negative psychological impact. Research has found CBT to have moderate to large effects on reducing depression and small effects on reducing burden (Pinquart & Sörenson, 2006; Gallagher-Thompson & Coon, 2007; Kinnear, 2012). The primary aims of the second meta-analysis were to investigate whether such benefits could extend to the dissemination of other evidence-based therapies including mindfulness and acceptance based interventions (MABIs) and indeed whether MABIs have the potential to yield larger effects on burden than CBT. The introduction describes the most established and evaluated MABIs alongside the rationale for why combining these approaches within a quantitative review is conceptually acceptable, and research demonstrating why these interventions may be particularly beneficial for informal caregivers of PwD.

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Chapter Three: The effectiveness of mindfulness and acceptance based interventions for informal caregivers of people with dementia: a meta-analysis

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MABIs for caregivers of people with dementia

**The effectiveness of mindfulness and acceptance based
interventions for informal caregivers of people with
dementia: a meta-analysis**

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Contributors: The first author designed the study, collected the data, analysed the title, abstracts and all full texts, conducted statistical analyses, interpreted the data and wrote the manuscript. The second author contributed to analysing full text articles and assessing eligibility, extracting the data and analysing the quality of selected studies, and editing and proof reading the manuscript. Both authors have approved the final manuscript.

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Abstract

Background and Objectives: The application of mindfulness and acceptance based interventions (MABIs) for informal caregivers of people with dementia (PwD) is relatively novel and the current state of the evidence base is unclear. This meta-analysis examined the effectiveness of MABIs on reducing symptoms of depression and burden in informal caregivers of PwD. The quality of studies was evaluated and moderator variables explored.

Research Design and Methods: A literature search of six electronic databases (PsycARTICLES, PsycINFO, MEDLINE Complete, SCOPUS, Web of Science and ProQuest) was conducted from the first available date to the 20th December 2016. Inclusion criteria involved studies that quantitatively investigated the impact of MABIs on depression and/or burden in informal caregivers of PwD.

Results: Twelve studies, providing data on 321 caregivers, were included. Most used Mindfulness Based Stress Reduction and were conducted in the USA. The average attrition among participants was 15.83%. The pre-post effect of MABIs was large for depression and moderate for burden. These effects were largely maintained at follow-up. Significant heterogeneity of effect sizes was observed, with no significant moderators identified. Study quality varied from very poor to moderately good.

Discussion and implications: The low attrition and moderate to large effects suggest that MABIs are acceptable and beneficial for informal caregivers of PwD. The lack of significant moderators could advocate services using more cost-effective forms of MABIs. Further higher quality research is needed to improve the robustness

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of the evidence base and enable a meta-analysis to thoroughly examine and quantify moderator variables.

Keywords: carers; burden; depression; effects.

Introduction

There are an estimated 47 million people with dementia (PwD) worldwide and 9.9 million new cases each year (World Health Organization, 2017). The majority of PwD are community dwelling and cared for by an informal caregiver; someone that provides physical, emotional and/or practical support for a person, based on social connection or kinship (Schulz & Martire, 2004). Informal caregivers improve the quality of life of PwD, delay the need for institutional care and save international governments billions of pounds every year (Brodaty & Donkin, 2009).

The effects of being an informal caregiver are diverse and complex. Research has found that five times as many caregivers of people with dementia fulfil diagnostic criteria for major depressive disorder compared to the general population (Cuijpers, 2005). They are also likely to experience greater perceived burden and depressive symptoms compared to caregivers of people without dementia (Pinquart & Sörensen, 2003; Ory, Yee, Tennstedt & Schulz, 2000). In this review 'burden' is conceptualised as the caregiver's perception of the degree to which the care-recipient is dependent upon them and their emotional health, physical health, social or financial status has declined as a result of the caring role (Zarit, Todd & Zarit, 1986).

There may be a number of reasons as to why these differences in emotional distress and burden have been observed. Practically, caregivers of PwD engage in a greater variety of care tasks, and a higher percentage provides 40 hours or more care per week compared to caregivers of people without dementia (e.g. Connell, Janevic & Gallant, 2001). Not only can this create employment complications and financial burden (Ory et al., 2000), but it could also impact upon the physical health of the caregiver and limit the amount of time the caregiver has for accessing support. In

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addition to this, due to the progressive nature of the disease, caregivers of PwD have to face the reality that the intellectual and emotional reciprocity they share with their loved one will increasingly deteriorate (Bertrand et al., 2006). Moreover, aggressive behaviours have been shown to increase the likelihood of the caregiver experiencing significant depressive symptoms and burden (Ornstein & Gaugler, 2012). It is important to note that there continues to be some uncertainty about whether long-term caregiving increases the risk for psychological difficulties or leads to some degree of adaptation (Tremont, 2011).

In order to ensure the affordability of care for PwD in the future, the world Alzheimer's report recommended that the coverage of caregiver interventions be increased so as to lessen burden and delay and reduce rates of transition into care homes (Alzheimer's Disease International, 2013). The research and recommendation demonstrate the need for interventions to be effective at decreasing burden and depressive symptoms.

Previous reviews have focussed on psychosocial interventions; primarily support groups, psychoeducation and counselling. These have found minimal and highly inconsistent evidence for their effectiveness on reducing burden or depressive symptoms (e.g., Cooke, McNally, Mulligan, Harrison & Newman, 2001; Dam, de Vugt, Klinkenberg, Verhey & van Buoxtel, 2016). In regards to evidence-based psychological treatments, cognitive-behavioural therapy (CBT) has been the most researched, with findings revealing small effects on burden and moderate to large effects on depression (Pinquart & Sörenson, 2006; Gallagher-Thompson & Coon, 2007; Kinnear, 2012). Indeed, the National Institute of Clinical Excellence (NICE, 2006) states that:

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“Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner” (NICE, 2006).

However, the guideline states that further research is needed to generate a better evidence base for its update (NICE, 2006). The promising findings of moderate to large effects of CBT on depression raises the question of whether such benefits could extend to the dissemination of other evidence based therapies such as mindfulness and acceptance based therapies. These approaches are receiving increased amounts of attention as potential treatments for various psychological difficulties including depression (e.g. Zettle, 2015). Moreover, given the small effect of CBT on burden, an investigation into the impact of other psychological approaches on this outcome is warranted.

The most established and evaluated mindfulness and acceptance-based interventions (MABIs) are Mindfulness Based Stress Reduction (MBSR; Kabat-Zinn, 1990), Mindfulness Based Cognitive Therapy (MBCT; Segal, Williams & Teasdale, 2002), Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999) and Dialectical Behaviour Therapy (DBT; Linehan, 1993).

MBSR has a strong focus on the formal practice of mindfulness meditations. It was designed for people with chronic pain and stress related conditions, but has been shown to be effective for depression (Fjorback, Arendt, Ørnbøl, Fink & Walach, 2011). MBCT was developed from MBSR and adapted to clients at risk of depressive relapse. It focuses on mindfulness practices and attempts to build participants' awareness of and disengagement from depressogenic cognitive processes and promotes behaviour-change strategies. It has strong empirical support

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for reducing depressive relapse (Fjorback et al., 2011) and emerging support for active depression (Finucane & Mercer, 2006).

ACT is based on behavioural principles and aims to promote psychological flexibility. It facilitates detachment from rigid rules or self-critical thoughts and acceptance and kindness towards oneself, non-judgemental present-focused awareness of internal experiences, and the discovery of what is most important to oneself and the establishment of larger patterns of effective action based on such values (Hayes et al., 1999). Mindfulness exercises are incorporated to enhance awareness and acceptance of thoughts and feelings. ACT has a strong evidence base for its effectiveness on depression (Zettle, 2015).

DBT is underpinned by a dialectical philosophy relating to the struggle of holding onto multiple “truths” (Linehan 1993). A key dialectic is balancing change and acceptance. DBT combines mindfulness with acceptance-based and cognitive-behavioural strategies focusing on facilitating interpersonal effectiveness, emotion regulation and distress tolerance. DBT was designed to treat suicidal women with self-injurious behaviours, but has been adapted for individual’s experiencing significant depressive symptoms (Lynch, Morse, Mendelsen & Robins, 2003).

The four MABIs differ in their level of focus on mindfulness meditation, their duration and the extent to which behaviour change strategies are taught. However, these MABIs share a coherent conceptual and practical foundation that warrants combining these approaches within a quantitative review (e.g., Baer & Huss, 2008). Firstly, they have overarching principles of the conceptualization of the mind, mental suffering and psychotherapeutic cure; all proposing that unpleasant cognitions, emotions and sensations are a part of life (Baer & Huss, 2008). Secondly,

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all emphasise the need to synthesise change and acceptance and the potential harm resulting from excessive experiential avoidance (Baer & Huss, 2008). Lastly, all apply Buddhist principles and techniques within a psychological framework to enable people to change the way they relate to experiences and facilitate valued action in the face of distress (Gore & Hastings, 2016).

There are several findings that indicate the potential benefit of MABIs for caregivers of PwD. The main coping strategies these individuals engage in are ‘wishing the problem would go away’ and ‘blocking and concealing emotions’; both of which heighten depressive feelings (Williamson & Schulz, 1993). Spira et al. (2007), broadens these findings in discovering a high and significant association between depressive symptoms and experiential avoidance in familial dementia caregivers. Therefore fostering mindfulness and acceptance of internal states may help caregivers of PwD to notice their struggles and relinquish unhelpful coping strategies; enabling depressive feelings to reduce. Research has also revealed that many caregivers of PwD disengage from services due to difficulties accepting the diagnosis and negative beliefs about dementia (La Fontaine et al, 2016). Krishnan, York, Backus and Heyn (2017) suggest that increasing acceptance in caregivers of people with neurodegenerative diseases may relieve caregiver burden. This could advocate the use of approaches aimed at promoting acceptance and a non-judgemental stance. Finally, most MABIs are short-term in nature which may be particularly beneficial for caregivers of PwD as the added demand to find alternative care for PwD can lead to increased burden.

A review of meditation-based interventions for informal caregivers of people with varying forms and severities of dementia found tentative evidence that they improve depressive symptoms and burden (Hurley, Patterson & Cooley, 2014).

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However, this included studies in which the primary intervention was the practice of mantram repetitions, based upon transcendental meditation or Kundalini Yoga Kirtan Kriya (e.g. Lavretsky et al, 2013). These practices are a distinct approach to meditation and not part of Buddhist-mindfulness (Shonin, Van Gordon & Singh, 2015). A recent systematic review concluded mindfulness-based interventions for informal palliative caregivers to be effective at reducing depression and burden (Jaffray, Bridgman, Stevens & Skinner, 2016). However, this included studies with caregivers of people without dementia. Given the experiential differences between caregivers of PwD and non-dementia caregivers, the conclusions of this review may not be reliably generalised. Moreover, both reviews were qualitative in nature and neither quantified the size of the treatment effect.

The application of MABIs for informal caregivers of PwD is a novel field. In order to clarify the current state of the evidence base, provide a direction of future research and inform dementia care guidelines, an effect-size analysis was conducted with the objectives:

- (1) to quantify the size of the treatment effects of MABIs on depressive symptoms and burden in informal caregivers of PwD using the maximum available data.
- (2) to assess the methodological quality of protocols used.
- (3) to explore factors that may moderate intervention effectiveness including intervention duration, contact time, study quality, intervention type and level of adaptation.

Method

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The meta-analysis adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Moher et al., 2009).

Eligibility Criteria

In accordance with the objective to use the maximum available data, the threshold for eligibility of study design criteria was not restrictive. Articles examining the pre and post or controlled effects of mindfulness and/or acceptance based interventions for informal caregivers of PwD were considered for analysis. This included randomized controlled trials (RCT), quasi-randomized controlled trials, both controlled and uncontrolled before and after studies. A study was classified as an RCT if individuals were prospectively assigned to one of two groups (one being the intervention) via a concealed randomization procedure. If a study used a quasi-method of allocation or if a concealed randomisation procedure was suspected but not stated, it was classified as a Quasi-RCT. Studies where participants were allocated to one of two groups without concealed- or quasi-randomization were identified as controlled before-and-after studies. Inactive comparators (waitlist or treatment as usual; TAU) and active comparators (alternative interventions where the mode of delivery, content and design were described) were included. In order to reduce the risk of publication bias, published and unpublished articles were considered for analysis.

Recognized MABIs (MBSR, MBCT, DBT and ACT) of any duration or format were included. Studies that combined elements, or focused on a specific element, from these approaches were included; providing that at least 50% of the intervention was devoted to mindfulness or acceptance based principles or practices. Protocols that were not mindfulness or acceptance based including those that used

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other forms of meditation (e.g. transcendental, concentration or Kundalini Yoga Kirtan Kriya) were excluded.

The population studied were informal unpaid caregivers of individuals with dementia. Caregivers were not required to have scored above a clinical cut-off for depression or received a depression diagnosis. No limits were set on gender, age, setting or time spent as a caregiver. Studies that delivered the intervention to both caregivers and care-recipients were included; providing that data for both were reported separately. Studies involving caregivers of people without dementia were excluded.

Articles were included if they used validated outcome measures for depression and/or burden at baseline and post intervention. Studies were excluded if insufficient data was provided or data overlapped with another included study.

Information sources

Published articles were primarily identified by searching PsycARTICLES, PsycINFO, MEDLINE Complete, SCOPUS and the citation database Web of Science. Unpublished articles including dissertations and theses were sought through ProQuest. Hand searches were performed on the reference lists of included studies and relevant systematic reviews and meta-analyses obtained via The Cochrane Online Library. All databases were searched from their inception to 20th December 2016.

Search

The search was performed by the first author. The key terms (Table 1) were searched for in the title of articles of all databases. No limits were applied to language. Foreign papers were translated into English.

Table 1. Search strategy and key terms

Concepts	Search terms
Type of intervention ¹	‘Mindfulness’ OR ‘mindfulness-based’ OR ‘meditation’ OR ‘mindfulness based’ OR ‘MBSR’ OR ‘MBCT’ OR ‘acceptance’ OR ‘acceptance-based’ OR ‘acceptance based’ OR ‘acceptance and commitment therapy’ OR ‘ACT’ OR ‘DBT’ OR ‘dialectical behaviour therapy’
Type of participants ²	‘Dementia’ OR ‘Alzheimer’s’ OR ‘Frail Elderly’ OR ‘cognitively impaired’ OR ‘caregiver’ OR ‘carer’ OR ‘care’ OR ‘caring’ OR ‘caregiving’ OR ‘family caregiver’ OR ‘family carer’ OR ‘informal caregivers’ OR ‘informal carer’
Combined	1 AND 2

Note: PsychARTICLES, PsychINFO, MEDLINE Complete were limited to journals, academic journals and dissertations, and SCOPUS search to articles and reviews.

Study selection

Search results were merged using EndNote software (version X8.0) and duplicate articles removed. Eligibility assessment was performed in a non-blinded manner. The initial screening of titles and abstracts was undertaken by the first author, whereby clearly irrelevant articles were excluded. One Spanish article was translated by a Research Associate, who was fluent in Spanish and English and had published dementia research. Full text articles were screened by both authors independently using a structured checklist (Appendix D1). The kappa coefficient was 0.59 indicating moderate agreement (Cohen, 1960). Disagreements between

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reviewers were resolved through discussions. It was unclear whether two studies met eligibility criteria and study authors were contacted for clarification.

Data collection process

The first author developed an electronic database which was pilot tested on a randomly-selected study by both authors collaboratively and refined accordingly. In order to reduce errors and minimise bias, data extraction was conducted on three randomly-selected studies by both authors independently and results compared, with no discrepancies identified. The first author independently extracted data from the remaining studies. Where data was missing or unclear, study authors were contacted. Data was transferred to the Comprehensive Meta-Analysis software (CMA V3; Borenstein, Hedges, Higgins, & Rothstein, 2005).

Data items

Data was extracted from each study based on the (1) characteristics of the trial (publication year, country, recruitment process, design, time points measures taken, sample size at all time points and whether intent-to-treat analysis was used, job title of facilitator, outcome measures, and follow up time in weeks); (2) characteristics of the intervention (intervention type, manual-based, adaptation level, length of session in minutes, number of sessions, day long retreat, total contact time and format); (3) characteristics of the control group, in controlled studies (sample size, mean age, type of control and type of treatment); (4) characteristics of the participants (mean age, age range, attrition, percentage female, average time spent as caregiver, relationship to patient, and the form of dementia the patient had and diagnostic procedure); (5) depression and caregiver burden outcome data (means, standard deviations, p values and correlations). The intervention type was defined

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according to the primary MABI used, unless the intervention appeared to be an equal combination of two or more MABIs and was classed as a 'multi-component MABI'. An intervention was deemed 'adapted' when the study authors stated that it had been tailored to suit the needs of informal caregivers of PwD (e.g., discussing concepts within the context of caregiving). If the authors did not explicitly state this then the intervention was classed as 'non-adapted'. One study provided outcomes from three subscales of a burden measure (Whitebird et al, 2012). The data from the subjective demand burden subscale was extracted as this seemed most similar to the burden measures used in the other included studies.

Information was not inputted if it was missing or unclear and not made available by study authors. There were two exceptions to this, where two studies did not clarify the day retreat length. These used a MBSR approach and it was assumed that the length of the retreat was that of the standardized program. Total contact time was calculated by multiplying session length by number of sessions and adding this to the length of the day retreat (if applicable). If a study included more than one control condition the data from the inactive condition (waitlist and TAU) was extracted. This was the most common comparison condition across the studies and it was deemed more important to evaluate the effectiveness of the intervention relative to its absence/treatment as usual (Hollon & Wampold, 2009).

Risk of bias in individual studies

A modified version of the RCT of Psychotherapy Quality Rating Scale (RCTPQRS; Kocsis et al., 2010) was used to calculate a score of and assign a qualitative description to the quality of included studies (see Appendix E1 supplementary material). This assesses 24 areas of study quality, including a

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description of individuals screened, included and excluded, the intervention, and adequacy of the sample size. A value of 0, 1 and 2 is assigned for each item, with an available total score of 48. The tool has been shown to have good internal reliability, internal consistency (Gerber et al., 2011) and external validity (Kocsis et al., 2010). The modified scale was pilot tested on a randomly selected study by both authors collaboratively and refined accordingly. Three randomly-selected studies were rated by both authors independently and results compared. Very few discrepancies were noted. These were resolved by choosing the most conservative score given on an item. The remaining studies were assessed by the first author independently.

Summary measures

Meta-analyses were conducted by computing Hedge's g (Hedge's & Olkin, 1985) in depression and burden outcomes using CMA.

Synthesis of results

Effect sizes (Hedge's g), their 95% confidence intervals (CI) and associated z and p values were computed using means and standard deviations when available. The effect sizes for one study were calculated using the p value. For pre-post intervention effect sizes, when the correlations between pre- and post-measures were not available, a conservative estimate ($r=0.7$) recommended by Rosenthal (1993) was used. To calculate the mean effect size (Hedge's g) for a group of studies, individual effect sizes were pooled using a random-effects model as the studies within each meta-analysis were not identical (e.g. did not have identical interventions). The mean Hedge's g and its 95% confidence interval (95% CI) were computed. To assess for heterogeneity among studies in each group, the chi squared statistic (Q ; Higgins & Thompson, 2002) and I squared statistic (I^2 ; Higgins,

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Thompson, Deeks & Altman, 2003) were computed. I^2 provides a percentage of the total observed variability in effect estimates that is due to heterogeneity rather than to chance and is not affected by low statistical power. An I^2 of 25% is considered low, 50% moderate and 75% high (Higgins et al., 2003).

Risk of bias across studies

To assess publication bias, funnel plots were constructed and the trim and fill method (Duval & Tweedie, 2000a) used to estimate how many studies could be missing from each meta-analysis, correct the funnel plot symmetry, and calculate adjusted effect size estimates. Rosenthal's Fail Safe N (Rosenthal, 1979) was calculated to determine how many studies averaging a null result would be needed to reduce overall treatment effects to non-significance. If only a few studies are required to nullify the observed effect (e.g. five or ten), it may not be robust (Borenstein, Hedges, Higgins & Rothstein, 2009).

Additional analyses

Random-effects meta-regression was conducted to investigate the relationship between intervention duration (no. of sessions), contact time (minutes), study quality and the pooled effect sizes, and random-effects sub-group analysis to determine whether effect sizes differed according to level of adaptation and intervention type. These analyses were performed on pre-post effect sizes when data from at least eight studies was available (Higgins & Thompson, 2004). A sensitivity analysis was conducted to determine the robustness of findings and whether conclusions would have differed substantially if a study including caregivers of people without dementia (Epstein-Lubow et al., 2011) was omitted.

Results

Study selection

The database searches resulted in 8041 articles (Fig. 1). After the removal of 3643 duplicates, the first author examined 4398 titles and abstracts and excluded 4370 articles. The full texts of the remaining 28 studies were screened, with 16 not fulfilling criteria (see Appendix F1 and G1) and 12 studies included in the meta-analysis (Table 2).

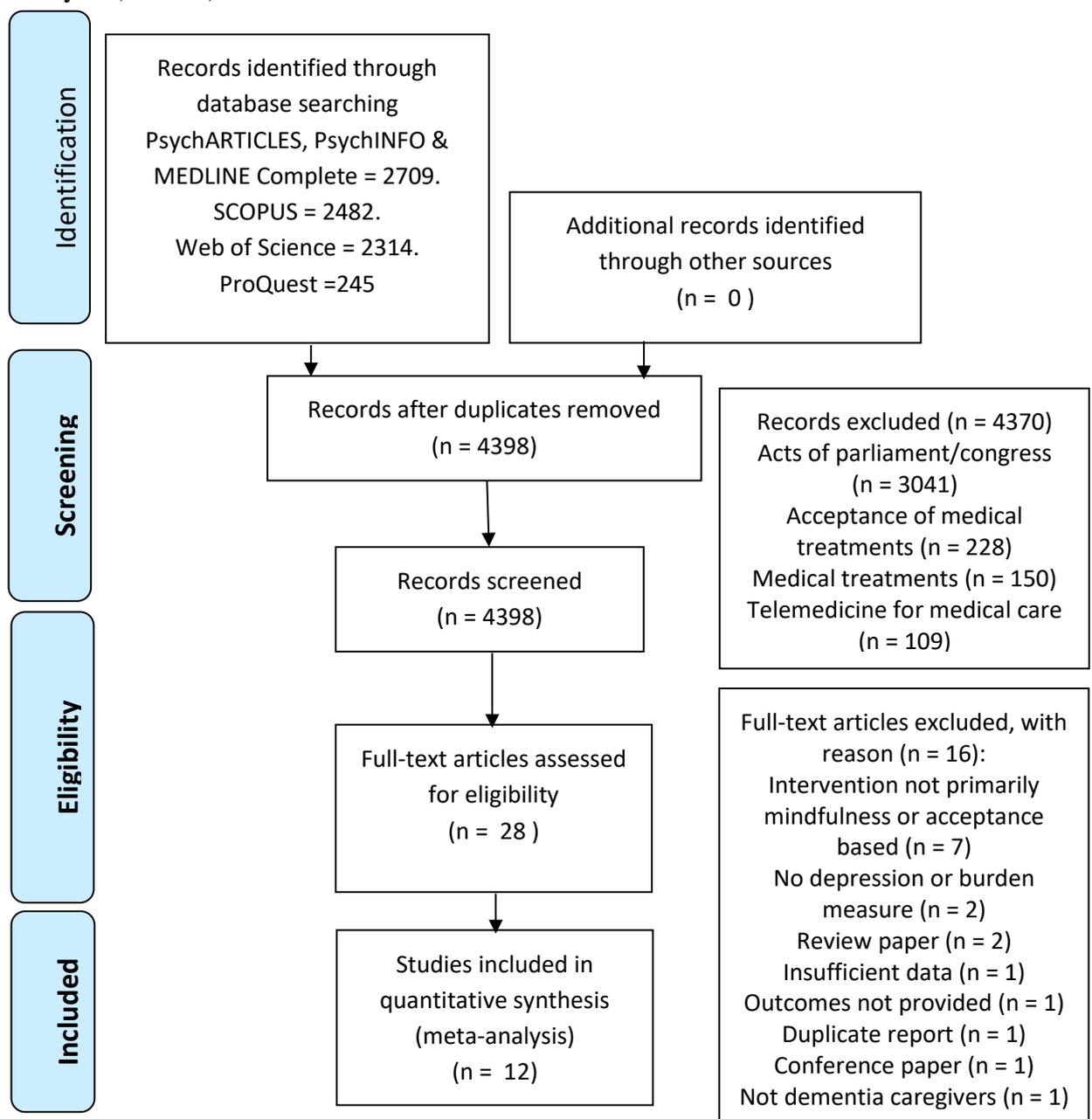


Fig.1. PRISMA flowchart of information from identification to inclusion of studies

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One study that recruited frail elderly caregivers (Epstein-Lubow, McBee, Darling, Arney & Miller, 2011) included two caregivers of people without dementia; however, as the majority of participants (77.8%) were caregivers of PwD, the authors decided to include this study. The hand searching of included studies and relevant reviews from The Cochrane Library did not yield any new articles.

Study characteristics

Table 3 presents the summary data for the 12 identified studies. The total number of participants was 321 (treatment = 207; control = 114). Ten studies reported the sample genders; one was predominantly male (38% female) and nine predominantly or all female (80 to 100%). Ten studies reported the mean age; ranging from 56.20 (SD = 7.70) to 71.60 (SD = 6.10). The average attrition among participants was 15.83%. Only four studies reported the diagnosis of the cared person and only three the procedure used to diagnose the condition. Of the four that reported the diagnosis, the majority had an Alzheimer's disease diagnosis - ranging from 53% to 100% of the sample. Three studies reported the average amount of months spent caregiving (see Table 3). There were five pre-post design studies and seven active/waitlist/TAU controlled studies. Interventions were predominantly MBSR (n = 6), followed by studies using one primary MABI (MBSR or MBCT) and incorporating elements from others (n = 2). The four remaining studies were MBCT, ACT, DBT and a 'multi-component MABI' (mindfulness practices combined with ACT metaphors). The ACT intervention was delivered in an individual format, and all others used a group format. Study durations ranged from 4-10 sessions and overall contact time from 240 to 1740 minutes. Eight studies were classed as using adapted interventions; a description of these can be seen in Table 3. Various depression and burden measures were used (also detailed in Table 3).

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Table 2: Key characteristics of included studies

Authors	Country	Study design	Recruitment Process	Relationship to care-recipient	Type and severity of dementia	Tool for dementia diagnosis	Intervention
Brown, Coogle and Wegelen (2015)	USA	RCT	Media, radio ads, posters and flyers disseminated at local Alzheimer's Association support groups and public community locations.	Spouse 52.17% Child 47.83%	Early stage Alzheimer's disease or other dementia	Stage 5 or lower on the FAST (Reisberg, 1988)	MBSR
Dioquino, Manteau-Rao and Madison (2016)	USA	BA	Recruited from among companions of dementia patients at a brain health centre by word-of-mouth and an advertising flyer.	Spouse 70% Child 30%	N/A	N/A	MBSR
Drossel, Fisher and Mercer (2011)	USA	BA	Referrals from dementia caregiver's individual therapists at a community clinic servicing PwD and their family.	Spouse 26.67% Child 73.33%	Unknown (moderate to severe cognitive impairment)	Physical and neurological assessments by neurologists.	DBT

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Epstein- Lubow, McBee, Darling, Armey and Miller (2011)	USA	BA	A diverse nursing home and home care clinical setting.	Spouse 22.22% Child 77.78%	N/A	N/A	MBSR
Franco, Sola and Justo (2010)	Spain	Quasi- RCT	Recruited through the University of Almería	N/A	Alzheimer's Disease	N/A	Mindfulness meditation and ACT metaphors
Hoppes, Bryce, Hellman and Finlay (2012)	USA	BA	E-mail, presentations to support groups for caregivers, and invitations to caregivers at an adult day-services centre.	Spouse: 63.64% Child: 36.36%	N/A. Some had "advanced dementia"	N/A	MBSR

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Losada et al. (2015)	Spain	RCT	Social and Health Care Centers as well as through Internet advertisement	Spouse 48.89% Child: 42.22% Relative 8.89%	Alzheimer's Disease 75.6%	N/A	ACT
Norouzi, Golzariand Sohrabi (2014)	Iran	Quasi- RCT	Referrals from the local Alzheimer's Association.	N/A	N/A	N/A	MBCT
O'Donnell (2013)	USA	Quasi- RCT	Magazine/newspaper advertisements, newsletters, presentations to caregiver support groups, retirement communities, and local chapters of Alzheimer's/Parkinson's disease societies	Majority spouses	32.14% Alzheimer's Disease 17.86% Mixed Dementia 25% Mild cognitive impairment 21.43% undiagnosed dementia 4.55% Lewy Body Dementia	N/A	MBSR
Oken et al. (2010)	USA	RCT	N/A	Spouse 70.00% Child 30.00%	N/A	N/A	MBCT with MBSR components

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Paller et al. (2015)	USA	BA	University Alzheimer's Disease Center, local advertisements, and word of mouth.	Spouse 65.00% Child 25.00% Relative 10.00%	Alzheimer's neuropathology 52.94%, mild cognitive impairment related to Alzheimer's Disease 11.76%, multiple strokes 11.76%, memory complaints without a diagnosis 17.65 %, frontotemporal dementia 5.88%	National institute on aging-Alzheimer's association workgroups on diagnostic guidelines for Alzheimer's disease (Albert et al., 2011).	MBSR (with DBT and ACT components)
Whitebird et al. (2012)	USA	RCT	A health plan and its clinics, community outreach, paid advertising (i.e., print and radio ads), press coverage, and word of mouth	Spouse, sibling and friend 32.60% Child 68.40%	N/A	N/A	MBSR

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Table 2 continued Key characteristics of included studies

Study Name	Level of adaptation to intervention	Comparator	Duration (no. sessions)	Contact time (minutes)	Follow-up (months)	Outcome measures		Quality (Descriptor)
						Depression	Burden	
Brown, Coogle and Wegelen (2015)	Adapted: discussions of caregiving; adjustments to mindfulness exercises to accommodate physical limitations.	Alzheimer's support group	8 (+ 1 day retreat)	1200	3	POMS-depression	ZBI	26 (average)
Dioquino, Manteau-Rao and Madison (2016)	Adapted: each session included a lecture on dementia or applying mindfulness with PwD e.g. "Aikido of dementia communication"	N/A	7 (+ 1 day retreat)	1200	6	PHQ-9	ZBI short form	8 (very poor)
Drossel, Fisher and Mercer (2011)	Adapted: discussions of caregiving; adaptation of Interpersonal Skills Training to guide effective communication in dementia.	N/A	8	1200	N/A	CES-D	CBI	17 (moderately poor)

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Epstein-Lubow, McBee, Darling, Armev and Miller (2011)	Adapted: Discussions of caregiving; applying training to stressful caregiving experiences; reduced session length and amount of home- practice. No extended 6-hr class; addition of lovingkindness meditation.	N/A	8	600	1	CES-D	ZBI	8 (very poor)
Franco, Sola and Justo (2010)	Non-adapted	Waitlist	10	1050	4	SCL-90-R	ZBI Spanish version	9 (very poor)
Hoppes, Bryce, Hellman and Finlay (2012)	Adapted: recognizing caregivers may have limited time for stress management, MBSR delivered at a 'lower-dose'	N/A	4	240	1	N/A	ZBI short form	10 (very poor)
Losada et al. (2015)	Adapted: a focus on unchangeable dementia-related behaviours/situations; values involved in caregiving; metaphors and mindfulness tailored for caregivers of PwD.	Support group/ workshop	8	720	6	CES-D	N/A	30 (moderately good)

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Norouzi, Golzariand Sohrabi (2014)	Non-adapted	Waitlist	8	1200	2	HRSD	CBI	8 (very poor)
O'Donnell (2013)	Non-adapted	PMR group	8 (+ 1 day retreat)	1740	2	GDS	N/A	24 (average)
Oken et al. (2010)	Dementia caregiving adapted	Respite-only	7	630	N/A	CES-D	N/A	23 (average)
Paller et al. (2015)	Adapted: recognizing the potential burden of being separated from PwD, session length reduced from 2 hr to 1.5 hr. First session was purely dementia psychoeducation.	N/A	8	720	N/A	GDS	N/A	9 (very poor)

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Whitebird et al. (2012)	Non-adapted	Education and support group	8 (+1 day retreat)	1500	6	CES-D	MBCBS	26 (average)
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Note. N/A = not available. Design: BA = Before-and-After study; Quasi-RCT = Quasi-Randomized Controlled Trial; RCT = Randomized Controlled Trial. Intervention: ACT = Acceptance and Commitment Therapy; DBT = Dialectical Behaviour Therapy; FAST = Functional Assessment Staging of Alzheimer’s Disease; MBCT = Mindfulness Based Cognitive Therapy; MBSR = Mindfulness Based Stress Reduction. Measures: CBI = Caregiver Burden Inventory (Novak & Guest, 1989); CES-D = Centre for Epidemiological Studies Depression Scale (Radloff, 1977); GDS = Geriatric Depression Scale (Yesavage et al., 1983); HRSD = Hamilton Rating Scale for Depression (Hamilton, 1980); MBDBC = Montgomery Borgatta Caregiver Burden Scale (Montgomery, 2002); PHQ-9 = Patient Health Questionnaire-9 (Kroenke, Spitzer & Williams, 2001); POMS-depression = Profile of Mood States-Depression (McNair, Lorr, & Droppleman, 1971); SCL-90-R = Symptom Checklist-90-Revised (Derogatis, 1994); ZBI = Zarit Burden Inventory 22-item (Zarit, Reever, & Bach-Peterson, 1980), 12-item (Bedard et al., 2001), Spanish version (Martín et al., 1996)

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Table 3. Pre to follow up depression and burden effect size data and post between group effect size data for depression.

Study	Pre to follow up depression					Pre to follow up burden					Post between-groups depression				
	Hedge's g	Lower limit	Upper limit	Z value	P value	Hedge's g	Lower limit	Upper limit	Z value	P value	Hedge's g	Lower limit	Upper limit	Z value	P value
Brown et al. (2015)	0.48	0.15	0.80	2.89	.004	0.42	0.10	0.74	2.55	.011	0.77	0.11	1.43	2.29	.022
Dioquino et al. (2016)	0.75	0.16	1.33	2.51	.012	0.60	0.05	1.16	2.12	.034	-	-	-	-	-
Epstein-Lubow et al. (2011)	-0.04	-0.50	0.42	-1.78	.859	0.56	0.06	1.06	2.20	.028	-	-	-	-	-
Franco et al. (2010)	0.56	0.20	0.93	3.06	.002	0.51	0.15	0.86	2.78	.005	1.22	0.52	1.92	3.41	.001
Hoppes et al. (2012)	-	-	-	-	-	0.45	-0.01	0.92	1.91	.056	-	-	-	-	-
Losada et al. (2015)	0.70	0.37	1.03	4.16	<.001	-	-	-	-	-	1.10	0.58	1.63	4.16	<.001

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O' Donnell (2013)	0.77	0.14	1.40	2.38	.017	-	-	-	-	-	0.97	0.16	1.77	2.36	.018
Norouzi et al. (2014)	2.51	1.56	3.47	5.13	<.001	0.76	0.25	1.26	2.91	.004	1.80	0.79	2.81	3.50	<.001
Oken et al. (2010)	-	-	-	-	-	-	-	-	-	-	0.29	-0.62	1.20	0.62	.533
Whitebird et al. (2012)	0.83	0.60	1.17	6.05	<.001	0.56	0.30	0.82	4.22	<.001	0.65	0.20	1.10	2.81	.005

Note. – denotes that the study did not include this data

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Risk of bias within studies

The total RCTQRS scores ranged from 8 (very poor) to 30 (moderately good), with a mean of 16.5 (SD = 8.70) and median of 13.50 (Table 3). Only one study demonstrated a check that the treatment studied was the treatment being delivered; through supervision and a measure of treatment receipt. The follow-up periods ranged from 1 to 12 months. Three studies provided a full description of drop outs or withdrawals. Of the seven controlled studies, two employed intent-to-treat (ITT) analysis and three provided full reports of appropriate randomization procedures.

Results of individual studies

Fig. 2 and Fig. 3 show forest plots of pre-post effect sizes (Hedge's g) for burden and depression, including 95% confidence intervals (CI) and associated z and p values. Pre-follow-up depression and burden effect sizes and post-intervention between-group depression effects can be seen in Table 3. Post-intervention between-group effects for burden were not analysed due to the limited number of controlled studies (most with small sample sizes) using this measure.

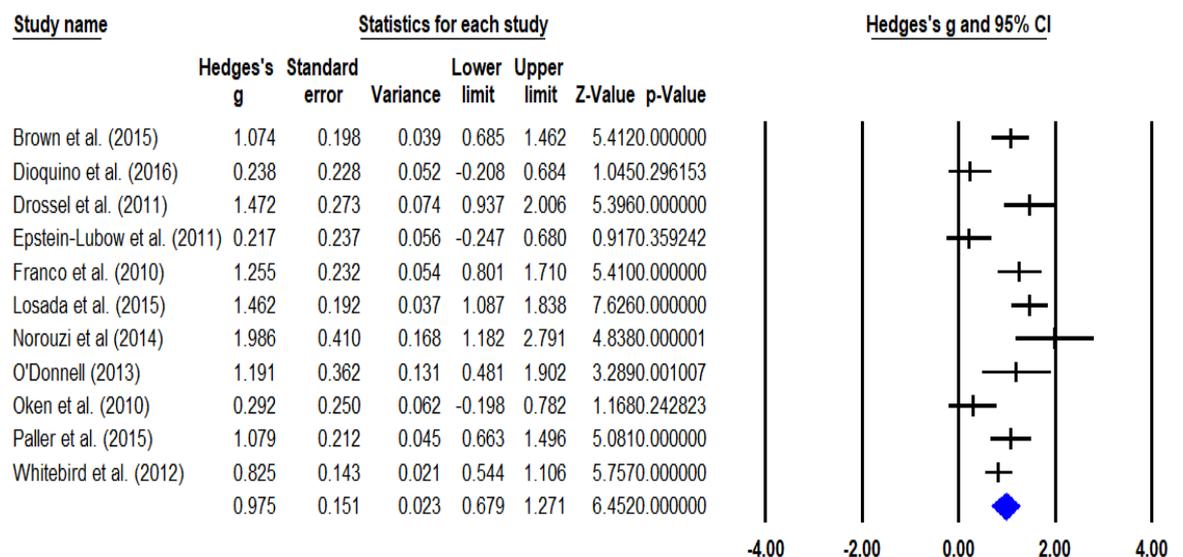


Fig 2. Pre-post effect sizes (Hedge's g) derived from studies examining the efficacy of mindfulness and acceptance based interventions for dementia caregivers – depression.

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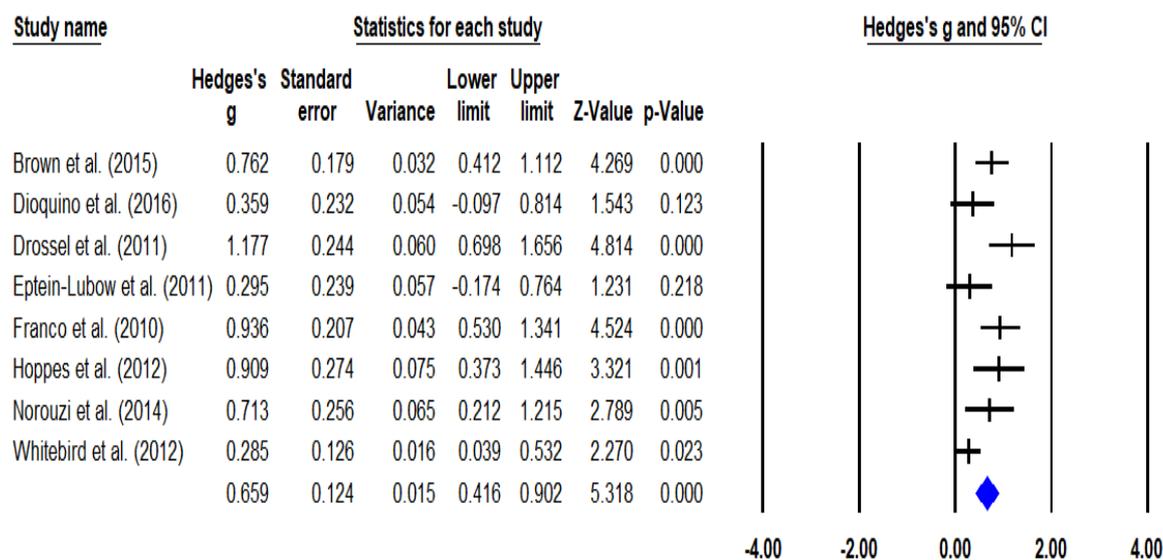


Fig 3. Pre-post effect sizes (Hedge's g) derived from studies examining the efficacy of mindfulness and acceptance based interventions for informal caregivers of PwD – burden.

Synthesis of results

Effects on depression

Eleven studies included pre-post measures of depression. These effect sizes varied from small ($g = 0.22$) to large ($g = 1.18$; fig 2). Overall, MABIs had a large effect on depressive symptoms pre- to post-intervention ($g = 0.98$; 95% CI 0.68 to 1.27, $p < .001$). However, the heterogeneity of these effect sizes was high ($I^2 = 78.79\%$, $Q = 47.15$). Seven controlled studies included depression measures; effect sizes of MABIs compared to controlled conditions ranged from small ($g = 0.29$) to large ($g = 1.80$) with an overall large effect ($g = 0.92$, CI 0.64 to 1.20, $p < .001$) and non-significant heterogeneity between these effects. Eight studies included depressive outcomes at follow-up; effect sizes ranged from a small negative effect ($g = -0.04$) to a very large positive effect ($g = 2.51$) with a medium mean effect size (g

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= 0.71, 95% CI 0.41 to 1.01, $p < .001$). However, heterogeneity of effect sizes was moderate to high ($I^2 = 74.51$, $Q = 27.47$).

Effects on Burden

Eight studies included pre-post burden measures. Effect sizes ranged from small ($g = 0.30$) to large ($g = 1.18$; fig 3), with a medium mean effect size ($g = 0.66$, CI 0.42 to 0.90, $p < .001$). However, heterogeneity of effect sizes was moderate ($I^2 = 64.04$, $Q = 19.47$). Seven studies included pre-follow-up burden outcomes. Effect sizes varied from small ($g = 0.42$) to medium ($g = 0.76$) with a medium mean pre-follow-up effect size ($g = 0.53$, CI 0.39 to 0.67, $p < .001$), with no significant heterogeneity of effect sizes ($I^2 < .001$, $Q = 1.50$).

Risk of bias across studies

Studies on depression

The mean pre-post effect size corresponded to a z value of 13.85 ($p < .001$) indicating that 539 studies with a null effect size would be needed before the combined two-tailed p -value would exceed 0.05, suggesting that the observed effect sizes may be robust. The trim and fill method indicated one potentially missing study that would need to fall on the left side of the mean effect size to make the plot symmetrical (Fig 4). Assuming a random-effects model, the new mean effect size reduced to Hedge's $g = 0.91$ (95% CI 0.61 to 1.21). The post between-groups intervention effect size corresponded to a z value of 7.23 ($p < .001$) indicating 89 studies with a null effect size would be needed to nullify these results. The trim and fill method suggested one potentially missing study that, if imputed using a random-effects model, would decrease the mean effect size to Hedge's $g = 0.85$ (95% CI 0.54 to 1.17). The pre-follow-up effect size corresponded to a z value of 9.19 ($p < .001$) indicating that 168 studies with a null effect size would be needed to nullify

the results. The trim and full method indicated two potentially missing studies that, if imputed under a random-effects model, would decrease the mean Hedge's g to 0.53 (95% CI 0.20 to 0.86).

Studies on burden

The mean pre-post effect size corresponded to a z value of 8.75 ($p < .001$) indicating that 152 studies with a null effect size would be needed before the combined two-tailed p -value would exceed 0.05, suggesting that the observed effect sizes may be robust. The trim and fill method suggested no missing studies (Fig 5). The pre-follow-up effect size corresponded to a z value of 7.06 ($p < .001$) indicating that 84 studies with a null effect size would be needed to nullify the results. The trim and full method indicated one potentially missing studies that, if imputed using a random-effects model, would decrease the mean Hedge's g to 0.51 (95% CI 0.37 to 0.65).

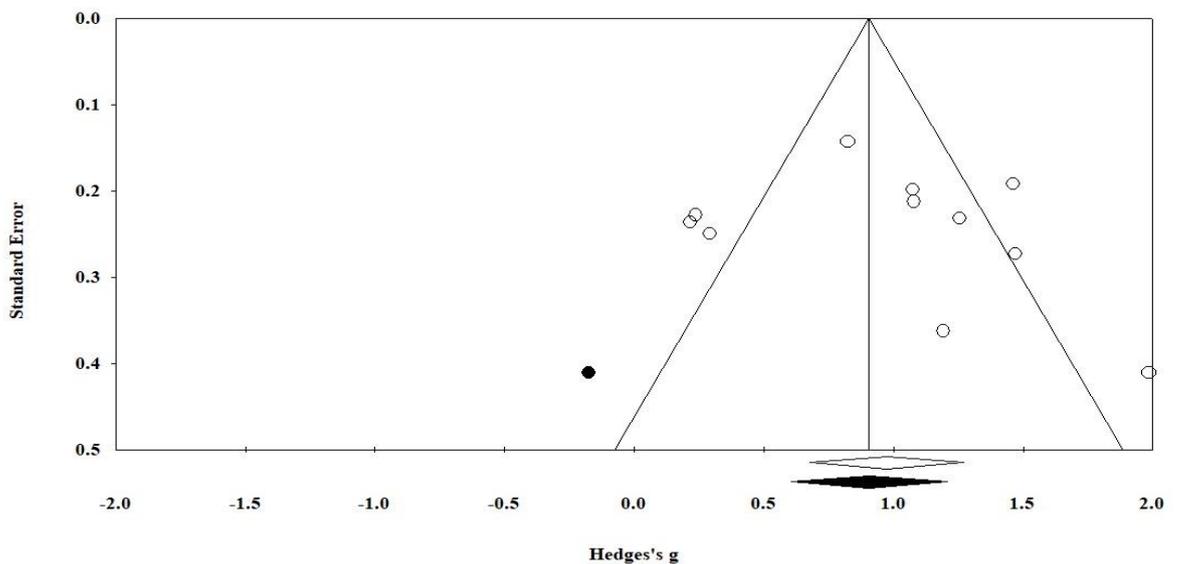


Fig 4. Funnel plot of Hedge's g pre-post depression effect sizes by standard error

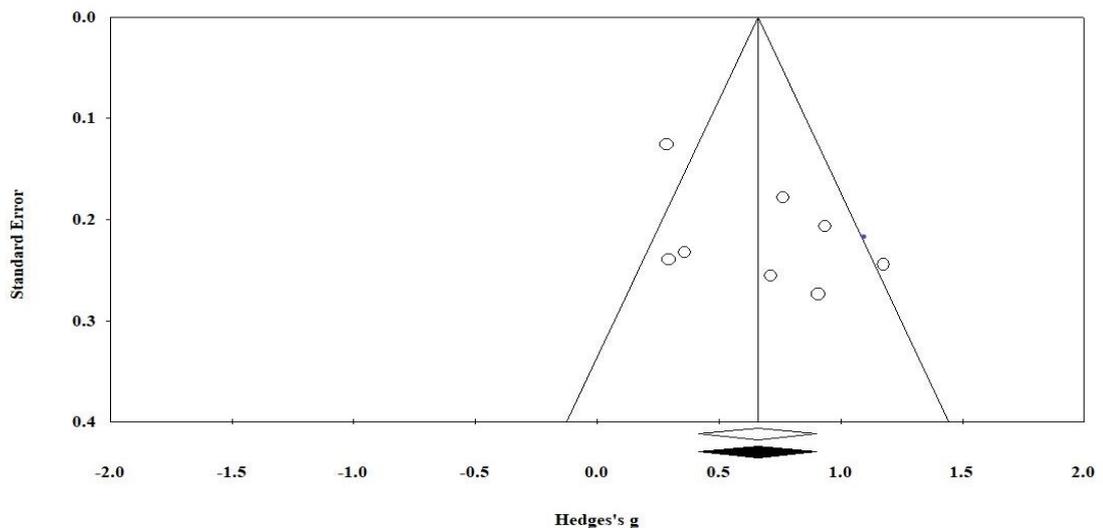


Fig 5. Funnel plot of Hedge's g pre-post burden effect sizes by standard error

Additional analyses

Meta-regression results

Regression coefficients were computed to investigate the differential effects of potential moderators on depression and burden pre-post effect sizes. The association between intervention duration and depression effect sizes approached significance (0.33, 95% CI -0.03 to 0.69, $p = .075$). There was a lack of relationship between contact time and depression effect sizes (0.0004, 95% CI -0.0005 to 0.001, $p = .374$), and study quality and depression effect sizes (0.01, 95% CI -0.03 to 0.05, $p = .601$). No significant associations were found between burden effect sizes and intervention duration (0.02, CI -0.17 to 0.17, $p = 0.983$), contact time (0.002, CI -0.008 to 0.005, $p = .618$), or study quality (0.004, CI -0.04 to 0.03, $p = .827$).

Sub group analysis

Adapted interventions did not significantly differ in effectiveness on depression ($p = 0.216$) or burden ($p = 0.776$) to non-adapted interventions. After removing data for the ACT, DBT and multi-component MABI (as each had one study), a sub-group analysis was performed comparing MBSR to MBCT finding no

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significant evidence that the impact on depression differed between these interventions ($p = 0.685$). Due to the limited number of studies and lack of sub-groups, analysis was not possible for burden outcomes.

Sensitivity analysis

All mean pre-post and pre-follow-up depression and burden effect sizes marginally increased, but remained within their qualitative descriptor (small, medium or large), bar the mean pre-follow-up depression effect size which increased from a medium to large effect ($g = 0.71$ to $g = 0.81$). The analysis found no deviations from the main analysis in terms of heterogeneity or significance of effect sizes.

Discussion

This appeared to be the first meta-analysis to explore and quantify the effects of MABIs on levels of depression and burden in informal caregivers of PwD. Twelve studies of varying research designs, providing data on 321 caregivers of diverse ages, were included in the analysis. The most promising finding of the review was that MABIs were largely effective at reducing levels of depression in informal caregivers of PwD from pre-to-post intervention. This effect decreased at follow up, moving into the medium effect size range; indicating that the gains lessened, but on the whole maintained over time. These results were very robust in the context of publication bias. There were fewer studies included in the analyses of post-intervention between group effects of controlled and MABI interventions, but a significant difference in depressive symptoms with large effect was found. This suggests that MABIs have a large effect on depressive symptoms compared to control conditions. Although the large effect is a similar finding to that of CBT on depressive symptoms in Piquart and Sörenson (2006), when compared with the

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result of Kinnear (2012), it indicates that MABIs may be more beneficial for reducing depressive symptoms. However, this is interpreted with caution due to the variance in methodologies across reviews.

The meta-analyses discovered that MABIs have a moderate effect on reducing burden in caregivers of PwD pre-to-post intervention; a finding that was very robust in the context of publication bias. Although the effect at follow-up may not be as reliable given the outcome of Rosenthal's fail safe N , it did suggest that gains were maintained over time. Unfortunately a comparison of the between group effect of burden for controlled studies was not conducted due to the limited number of studies that employed this measure. However, given that CBT has been found to have small effects on burden (e.g. Kinnear, 2012), the moderate effect found in the current analysis could indicate MABIs to be viable alternatives to CBT.

In addition to the findings demonstrating the effectiveness of MABIs on reducing depressive symptoms and burden, the average attrition among participants was relatively low (15.83%); lower than the expected rate for adults engaging in a psychological intervention (Swift & Greenberg, 2012). This demonstrates that MABIs are acceptable for this population. It is possible that the low attrition is linked to the underlying mechanisms of change within MABIs. As previously discussed, a strong association has been found between experiential avoidance and depressive symptoms in caregivers of PwD and the engagement of caregivers in services has been linked to a struggle with acceptance of the diagnosis and negative beliefs about dementia (La Fontaine et al., 2016). Therefore caregivers of PwD may be more likely to continue a therapy that reduces experiential avoidance, increases acceptance of internal and external experiences, and develops a non-judgemental stance.

Limitations

The meta-analysis found that there was significant moderate to high heterogeneity among several of the depression and burden effect estimates. This suggests that these effects are not similar across studies and any conclusions drawn are limited by this fact. Sub group analysis of intervention type was extremely limited due to the small number of included studies and lack of sub groups. Most studies used an MBSR intervention, followed by MBCT. A comparison of MBSR to MBCT for effectiveness on depressive symptoms revealed no significant difference. The heterogeneity was also not explained by the intervention duration, contact time, study quality or level of adaptation. Therefore the factors contributing towards the heterogeneity among pre-post depression effect sizes remains unknown. Interestingly, heterogeneity was low and non-significant among the post between-group depression effects, suggesting that the variation in these effects was not greater than what would be expected by chance. Taken together, these findings may indicate the appropriateness of healthcare providers delivering cost effective forms of MABIs; lower-dose and derived from a standardised manual. However, the analyses may have been underpowered to detect the presence of heterogeneity or significant moderators for the heterogeneity that was present.

Another limitation of the meta-analysis was the quality of included studies. Although study quality was not a significant moderator for the effectiveness of MABIs, overall study quality was relatively poor. The majority of the sample sizes within the included studies were small. There was a lack of RCTs, thus the current meta-analysis did not focus solely on RCTs, and only two of these employed ITT analysis. Many studies also failed to provide a full description of the diagnoses of the care-recipient and diagnostic procedure. Therefore the review cannot reliably state

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that all of the caregivers were caring for someone with dementia, given that some may not have received a formal diagnosis. However, what was most apparent was a consistent lack of treatment adherence measurement.

A third limitation of the meta-analysis is that it examined only depression and burden outcomes. It therefore cannot provide evidence for the effectiveness of MABIs on other outcomes such as anxiety, which has been found to be highly prevalent in caregivers of PwD (Cooper, Balamurali & Livingston, 2007). The decision to focus on depressive symptoms and burden was based upon the prevalence of these difficulties in caregivers of PwD, the recommendations of the World Alzheimer's report (Alzheimer's Disease International, 2013) and the limited number of MABIs that measured outcomes such as anxiety.

Conclusion and future directions

The meta-analysis discovered that the average attrition of participants was relatively low, indicating that MABIs are acceptable for this population. The findings revealed that MABIs are largely effective at improving symptoms of depression, and moderately effective at reducing burden in informal caregivers of PwD. Moderate to significant heterogeneity was observed in almost all effect sizes. Unfortunately, the study did not find significant moderator variables to account for these observations. This may suggest that variables not assessed were contributing towards heterogeneity, and/or that the analyses were underpowered. The results warrant further research, using more rigorous methodology into the effectiveness of MABIs for informal caregivers of PwD. In particular, to improve the reliability of findings, future studies should strive to include the diagnoses of the individuals with dementia and the procedure/s used to ascertain these. The use of more robust methodologies could enable a future meta-analysis to thoroughly explore and

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quantify moderator variables in order to establish optimization of MABIs for informal caregivers of PwD. Finally, the majority of included studies involved a female dominated sample; although this is representative of the current demographic (Alzheimer's Research UK, 2015) and in fact of caregivers of individual's with other neurological conditions (e.g. Krishnan et al., 2017), it may be helpful for future research to explore the impact of MABIs for male caregivers of PwD specifically.

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Supplementary Material

Appendix A1

Submission guidelines for *The Gerontologist*

AIMS AND SCOPE OF THE JOURNAL

The Gerontologist is a bimonthly journal of The Gerontological Society of America that provides a multidisciplinary perspective on human aging primarily through the publication of research that is relevant to social policy, program development, and service delivery. It reflects and informs the broad community of disciplines and professions involved in understanding the aging process and providing service to older people. Articles, including those in applied research, should include a conceptual framework and testable hypotheses, and report research findings with implications for policy or practice. Contributions from social and psychological sciences, biomedical and health sciences, political science and public policy, economics, education, law, and the arts and humanities are welcome. Brief descriptions of innovative practices and programs are appropriate in the Intervention Research section. Please refer below to the Types of Manuscripts Considered for additional information about all types of manuscripts.

Due to the high volume of submissions, we are unable to offer pre-screening advice.

Instead, please refer to the aims and scope of the journal to determine if *The Gerontologist* is a suitable journal for your work.

TYPES OF MANUSCRIPTS CONSIDERED BY THE GERONTOLOGIST

All manuscripts submitted to *The Gerontologist* should address practice and/or policy implications.

***The word limits listed below include abstract, text, and references.**

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- Tables and figures are limited to 5 Word pages for all submission types except for Review Articles, for which 10 pages are allowed.
- To manage the word and page counts, authors are encouraged to submit detailed methodology, tables, and/or figures as appendixes. If your manuscript is accepted, appendixes are available to readers online only.

a. **Intervention Research.** An Intervention Research submission describes research that spans the trajectory from intervention development to implementation.

Appropriate articles include rigorous early stage development, feasibility, or pilot studies of innovative practices, RCTs, studies of the transportability of efficacious interventions, community testing or trials, and tests of dissemination and implementation strategies. Submissions may be research article length (maximum of 6000 words for quantitative, 7000 words for qualitative or mixed methods), or brief reports (maximum of 2500 words; may be most appropriate for pilot studies).

Successful submissions will have the following attributes: (a) a clear theoretical or conceptual framework supporting the intervention and/or the treatment development and implementation process, (b) for implementation research, a description of evidence from rigorous research that the intervention has efficacy, (c) methodological rigor, including clear articulation of the design and analyses, and (d) integration of implementation considerations regardless of research stage. For more information, please refer to the following editorial: Meeks, S. & Pruchno R. (2017). Practice Concepts Will Become Intervention Research Effective January 2017. *The Gerontologist*. 57(2), 151-152. doi: 10.1093/geront/gnw213

b. **Research Articles.** Research Articles present the results of original research.

These manuscripts may be no longer than 6,000* (7,000* for qualitative studies) words. The word count includes; abstract, text and references. Tables and figures are

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limited to 5 Word pages. The text is usually divided into sections with the headings:

Introduction, Design and Methods, Results, and Discussion and Implications.

Subheadings may also be needed to clarify content. Research design and analysis procedures as well as implications for practice or policy must be clearly described.

Qualitative Manuscripts: Qualitative manuscripts should avoid the subheading "A Qualitative Study." See Schoenberg, N., & McAuley, W. J. (2007). Promoting qualitative research. *The Gerontologist*, 47(5), 576–577 and Schoenberg, N.E., Miller, E.A., and Pruchno, R., The Qualitative Portfolio at *The Gerontologist*: Strong and Getting Stronger. *The Gerontologist* (2011) 51(3): 281–284.

Humanities and Arts: Please refer to the following editorial for additional detail with these types of submission: Kivnick, H.Q. & Pruchno, R. (2011). Bridges and Boundaries: Humanities and Arts Enhance Gerontology, *The Gerontologist*, 51(2), 142-144.

c. **Review Articles.** The *Gerontologist* welcomes submissions of state-of-the-art Review Articles (e.g. systematic/scoping reviews, umbrella reviews) and/or in-depth synthesis methodology reviews (e.g. meta-analyses). Manuscripts should be limited to 8,000* words. Authors are encouraged to use and include the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist when submitting the manuscript. Please make sure to upload the appropriate checklist and flow diagram with your review (PRISMA checklist and flow diagram is available here). Note: It is permissible to add a column or space to the checklist that specifies where in the manuscript each component has been followed. Review Articles will be published online only (title would appear in a print issue Table of Contents for the journal, but the article would appear online only). Articles will go through our usual peer review and editing processes. They will receive a DOI, be

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searchable, and will be available electronically.

d. **Measurement Articles.** Measurement articles describe the reporting of sophisticated scale/instrument development procedures (6,000* words; all scales must be freely available for use by researchers). Measurement articles will be published online only (title would appear in a print issue Table of Contents for the journal, but the article would appear online only). Articles will go through our usual peer review and editing processes. They will receive a DOI, be searchable, and will be available electronically.

e. **Brief Reports.** Brief reports are encouraged for significant and innovative papers that are not as long as full research articles, but are equivalent in quality. Manuscripts should be no more than 2,500* words. The word count includes the abstract, text and references.

f. **Forum.** Timely scholarly review articles or well-documented arguments presenting a viewpoint on a topical issue are published in this section. Total length should be no more than 5,000* words. The word count includes the abstract, text and references.

g. **On Film and Digital Media.** Please refer to the editorial "Launching 'On Film and Digital Media."

h. **Book Reviews.** Book reviews are published in an essay form. Reviews are prepared at the request of the Book Review Editor and are not guaranteed for acceptance prior to submission. Unsolicited book review essays are not accepted. Books for review should be sent to Jamila Bookwala, PhD, Book Review Editor, Office of the Provost, 219 Markle Hall, Lafayette College, Easton, PA 18042.

i. **Guest Editorials.** Upon occasion, the Editor-in-Chief will invite guest editorials. Unsolicited editorials are not accepted.

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The Gerontologist does not publish obituaries, speeches, announcements of programs, or new product information.

Supplement issues of *The Gerontologist* are additional and externally funded issues.

Please contact the editorial office at tg@geron.org for further information. *The*

Gerontologist also publishes special issues, developed by the editors of *The*

Gerontologist within our regularly scheduled bimonthly issues.

FORMATTING

Manuscripts are to be submitted in Microsoft Word or a Word-compatible program at [ScholarOne](#). Manuscripts submitted in other formats will be unsubmitted and returned to the corresponding author for correction prior to editor review. Please DO NOT submit PDF versions of your manuscript submission materials. A peer-review title page will be created by the system and will be combined with the main document file into a single PDF document. This document will be used for the peer review process.

The Gerontologist uses **APA style**. General guidelines follow; for more detailed information, consult the *Publication Manual of the American Psychological Association* (6th ed.). Please see section TYPES OF MANUSCRIPTS

CONSIDERED BY THE GERONTOLOGIST above for additional information about the types of submissions and word counts. Please read “Editorial: Science or Fishing?” for valuable information about manuscript preparation.

This journal has a double-blind review policy. Therefore, we require authors to submit TWO versions of the article file, anonymous and non-anonymous (see below for additional information). Please upload ONLY these two files, the anonymous and

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non-anonymous manuscript files. Include your tables and/or figures and appendices, if applicable, in these documents, following APA guidelines.

Abbreviations: Ensure that the use of abbreviations is clear and that each one is defined in the text at its first mention only.

In-text References and Citations. Refer to the *Publication Manual of the American Psychological Association* (6th ed.) for style and see the **FORMATTING** section above. References in text are shown by citing in parentheses the author's surname and the year of publication. Example: “. . . a recent study (Jones, 1987) has shown. . . .” If a reference has two authors, the citation includes the surnames of both authors each time the citation appears in the text. When a reference has more than two authors and fewer than six authors, cite all authors the first time the reference occurs. In subsequent citations, and for all citations having six or more authors, include only the surname of the first author followed by “et al.” Multiple references cited at the same point in the text are in alphabetical order by author's surname.

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COMPONENTS OF THE MANUSCRIPT

Cover Letter (Optional). A cover letter is not required and is optional. It should explain how the manuscript is innovative, provocative, timely, and of interest to a broad audience, and other information authors wish to share with editors. Note: The cover letter for manuscripts will NOT be shared with reviewers.

Title page. A title page should be a completely separate page that includes the following:

- (1) Title of the manuscript, APA recommends that a title be no more than 12 words.
- (2) **All** authors' full name(s), affiliations, and email addresses.
- (3) The corresponding author should be clearly designated.

Abstract and Keywords. On a separate page On a separate page, each manuscript must include a brief abstract. Structured abstracts for Research Articles, Brief Reports, and Intervention Research, Review Articles, and Measurement Articles submissions should be approximately 250 words (the web-based system will not accept an abstract of more than 250 words), and must include the following headings: **Background and Objectives, Research Design and Methods, Results, and Discussion and Implications.** Forum manuscripts must also include an abstract of about 200 words, but may be without structured headings.

Below the abstract, authors should supply three to five keywords that are NOT in the title. Please avoid elders, older adults, or other words that would apply to all

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manuscripts submitted to *The Gerontologist*. Note: Three keywords must be entered to move forward in the online submission process.

Text. The text of Research Articles, Brief Reports, and Intervention Research, Review Articles, and Measurement Articles submissions should follow the headings included in the structured abstract (see above Abstract and Keywords). Forum manuscripts should also be divided into headings, as appropriate for the submission. Articles may need subheadings within some sections to clarify their content. The Implications should not merely restate the results but should interpret the results and specify the policy and/or practice implications.

(1) The word counts for the different types of publications considered by the Journal are presented above and are inclusive of the abstract, text, and references.

(2) If manuscripts greatly exceed these word count limits, your manuscript may be returned to you for correction BEFORE the peer review process can begin. If you would like to appeal the word count limit for the text of the manuscript, permission must be granted by the Editor in Chief prior to submission. When submitting, please indicate in your cover letter that permission has been granted.

Acknowledgment (Optional). If the authors choose to include acknowledgments recognizing funders or other individuals, they should be placed on a separate page immediately following the title page. The self-identifying acknowledgments should be removed from the anonymous version of the manuscript.

Conflict of Interest. At the point of submission, each author should reveal any financial interests or connections, direct or indirect, or other situations that might

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raise the question of bias in the work reported or the conclusions, implications, or opinions stated - including pertinent commercial or other sources of funding for the individual author(s) or for the associated department(s) or organization(s), personal relationships, or direct academic competition. When considering whether you should declare a conflicting interest or connection please consider the conflict of interest test: Is there any arrangement that would embarrass you or any of your co-authors if it was to emerge after publication and you had not declared it?

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The following rules should be followed:

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- The full official funding agency name should be given, i.e. 'National Institutes of Health', not 'NIH' (full RIN-approved list of UK funding agencies) Grant numbers should be given in brackets as follows: '[grant number xxxx]'
- Multiple grant numbers should be separated by a comma as follows: '[grant numbers xxxx, yyyy]'
- Agencies should be separated by a semi-colon (plus 'and' before the last funding

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agency)

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An example is given here: ‘This work was supported by the National Institutes of Health [AA123456 to C.S., BB765432 to M.H.]; and the Alcohol & Education Research Council [hfygr667789].’

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Journals: Kaskie, B., Imhof, S., Cavanaugh, J., & Culp, K. (2008). Civic engagement

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as a retirement role for aging Americans. *The Gerontologist*, 48, 368–377.

doi:10.1093/geront/48.3.368

Books: Quadagno, J. S. (1982). *Aging in early industrial societies*. New York: Academic Press.

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Type table titles and figure captions on a separate page following the references in

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Supplementary material can be made available by the publisher online only and linked to the published article. This material includes supporting material that is not essential for inclusion in the full text to understand the conclusions of the paper but contains data that is additional or complementary and directly relevant to the article content and therefore may benefit the reader. Such information might include more detailed methods, extended data sets/data analysis, or additional figures.

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Appendices

All appendices will be published online only as supplementary material (please see FORMATTING and Supplementary Material instructions above).

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Supplementary Material

Appendix B1

Email communication from The Gerontologist stating acceptance of article

25-Feb-2018

Dear Miss Collins,

Congratulations! It is a pleasure to accept the manuscript titled "The effectiveness of mindfulness and acceptance based interventions for informal caregivers of people with dementia: a meta-analysis" authored by Collins, Rebecca; Kishita, Naoko, in its current form for publication in The Gerontologist.

You will be receiving a separate email from the production team which will include a copyright form. This form must be signed and returned before the article can be published. Please note the instructions on the copyright form. You will be contacted by the Production Editor when it is in production and being copyedited, at which point the manuscript will be returned to you for response and final proofing.

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Thank you for your fine contribution. On behalf of the Editors of The Gerontologist, we look forward to your continued contributions to the Journal. It has been a pleasure working with you on this manuscript.

Warmest regards,
Patricia C. Heyn, Ph.D., FGSA, FACRM

Supplementary Material

Appendix C1

Copyright agreement to Publish with The Gerontologist

Journal: The Gerontologist DOI: 10.1093/geront/gny024

Title: The effectiveness of mindfulness and acceptance based interventions for informal caregivers of people with dementia: a meta-analysis

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Supplementary Material

Appendix D1

Eligibility criteria checklist

Study Characteristics	Eligibility criteria <i>(Insert inclusion criteria for each characteristic as defined in the Protocol)</i>	Eligibility criteria met?			Location in text or source (pg & ¶/fig/table/ other)
		Yes	No	Unclear	
Type of study design	Randomised controlled trial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Controlled before-and-after study	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Before-and-after comparison	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Quasi randomised controlled trial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Study language	English	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Japanese	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Participants	Informal caregivers of someone with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Informal caregivers of someone with dementia and the cared-for person with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Types of intervention	Mindfulness-based cognitive therapy (MBCT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Mindfulness-based stress reduction (MBSR)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Acceptance and commitment therapy (ACT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Pure mindfulness or acceptance intervention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Other multi-component acceptance/mindfulness based therapy (e.g.DBT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Types of outcome	Depression symptom measure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Level of caregiver burden measure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
INCLUDE <input type="checkbox"/>		EXCLUDE <input type="checkbox"/>			

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Reason for exclusion

Notes:

Supplementary Material

Appendix E1

Adapted-RCT of Psychotherapy Quality Rating Scale (RCT-PQRS)

Description of subjects

Item 1. Diagnostic method and criteria for inclusion and exclusion

0	poor description and inappropriate method/criteria
1	full description or appropriate method/criteria
2	full description and appropriate method/criteria

A rating of 2 requires;

- Full details of the diagnosis of the care recipient and diagnostic procedure AND
- Description of participants – including that they were **ALL** informal caregivers AND details the caregiver-care-recipient relationship AND
- Detailed description of inclusion and exclusion criteria for participants

Item 2. Documentation or demonstration of reliability of diagnostic methodology

0	poor or no reliability documentation
1	brief reliability documentation (documentation in the literature is sufficient, even if it is not explicitly cited)
2	full reliability documentation (documentation of within-study reliability necessary)

A rating of 2 requires;

- The outcome measure/s used for screening is/are stated to be reliable and valid with a reference cited AND
- Inter-rater reliability is tested within the study.

Item 3. Description of relevant comorbidities

0	poor or no description of relevant comorbidities
1	brief description of relevant comorbidities
2	full description of relevant comorbidities

A rating of 2 requires;

- Full description of caregiver's comorbid mental health difficulties e.g. depression, or explicitly states that all participants with comorbid mental health difficulties (with details of types of difficulties) were excluded.

Item 4. Description of numbers of subjects screened, included, and excluded

0	poor or no description of numbers screened, included, and excluded
1	brief description of numbers screened, included, and excluded
2	full description of numbers screened, included, and excluded

MABIs for caregivers of people with dementia

A rating of 2 requires;

- Presentation of detailed description of numbers of participants screened using a flow chart AND
- Detailed description of screening procedure (e.g., a therapist conducted screening assessments)

Definition and delivery of treatment

Item 5. Treatment(s) (including control/comparison groups) are sufficiently described or referenced to allow for replication

0	poor or no treatment description or references
1	brief treatment description or references (also if full description of one group and poor description of another)
2	full treatment description or references (manual not required)

A rating of 2 requires;

- Full treatment description is provided to allow for replication (i.e., detailed description for each session) for all conditions (including control/comparison)

OR

- There is reference to a well-established manualised treatment (e.g. mindfulness-based stress reduction by Kabat Zinn, 1979). Note: if the intervention has been adapted in anyway then this must be explicitly stated and explained or a reference to the new treatment provided.

Item 6. Method to demonstrate that treatment being studied is treatment being delivered (only satisfied by supervision if transcripts or tapes are explicitly reviewed)

0	poor or no adherence reporting
1	brief adherence reporting with standardized measure or full adherence reporting with non-standardized measure (eg, non-independent rater)
2	full adherence reporting with standardized measure (must be quantitative and completed by an independent rater)

A rating of 2 requires;

- There is evidence that the facilitator/s delivering the intervention/s were supervised, either within a group or one to one, to monitor adherence to the intervention methods AND
- Either a measure by supervisors was used to monitor therapist's adherence to treatment model OR participants completed outcome measures that demonstrate a good knowledge of the key principles and skills learnt relating to the intervention provided.

Item 7. Therapist training and level of experience in the treatment(s) under investigation

0	poor description and underqualified therapists
1	full description or well-qualified therapists

2	full description and well-qualified therapists
---	--

A rating of 2 requires;

- Description of the facilitator/s job role AND
- Description of the facilitator/s level of training (i.e. at university, MSc, BSc,) AND
- Evidence that therapists had extensive experience in the intervention being delivered OR it is stated that they have received specific training in the intervention being delivered.

Item 8. *Therapist supervision while treatment is being provided*

0	poor description and inadequate therapist supervision
1	full description or adequate therapist supervision
2	full description and adequate therapist supervision

A rating of 2 requires;

- Supervision is provided throughout the treatment from highly qualified therapists (Clinical Psychologists or over-seas equivalents) or by experienced professionals that have been highly trained in the type of intervention being delivered. Detailed description of supervision being offered (e.g. receiving weekly supervision) needs to be provided.

Item 9. *Description of concurrent treatments (eg, medication) allowed and administered during course of study*

0	poor or no description of concurrent treatments
1	brief description of concurrent treatments
2	full description of concurrent treatments

If patients on medication are included, a rating of 2 requires full reporting of what medications were used; if patients on medications are excluded, this alone is sufficient for a rating of 2.

Outcome measures

Item 10. *Validated outcome measure(s) (either established or newly standardized)*

0	poor or no validation of outcome measure(s)
1	brief validation of outcome measure(s) (shown or cited)
2	full validation of outcome measure(s) (shown or cited)

Item 11. *Primary outcome measure(s) specified in advance*

0	poor or no specification of primary outcome measure(s) in advance
1	brief specification of primary outcome measure(s) in advance
2	full specification of primary outcome measure(s) in advance

Item 12. *Outcome assessment by raters blinded to treatment group and with established reliability*

This item applies only when clinician-rated outcome measures (e.g., Hamilton Depression Rating Scale) are used in the study. Established reliability requires the interrater agreement for the assessment.

0	poor or no blinding of raters to treatment group (eg, rating by therapist, non-blind independent rater, or patient self-report) and reliability not reported
1	blinding of independent raters to treatment group or established reliability
2	blinding of independent raters to treatment group and established reliability (eg, interrater agreement for the assessment reported)

Item 13. *Discussion of safety and adverse events during study treatment(s)?*

0	poor or no discussion of safety and adverse events
1	brief discussion of safety and adverse events
2	full discussion of safety and adverse events (for example if a caregiver's relative died)

Item 14. *Assessment of long-term posttermination outcome (should not be penalized for failure to follow comparison group if this is a waitlist or nontreatment group that is subsequently referred for active treatment)*

0	poor or no posttermination assessment of outcome
1	medium-term assessment of posttermination outcome (2-12 months posttermination)
2	long-term assessment of posttermination outcome (≥ 12 months posttermination)

Data analysis

Item 15. *Intent-to-treat method for data analysis involving primary outcome measure*

0	no description or no intent-to-treat analysis with primary outcome measure
1	partial intent-to-treat analysis with primary outcome measure
2	full intent-to-treat analysis with primary outcome measure

Item 16. *Description of dropouts and withdrawals*

0	poor or no description of dropouts and withdrawals
1	brief description of dropouts and withdrawals
2	full description of dropouts and withdrawals (must be explicitly stated and include reasons for dropouts and withdrawals)

Item 17. *Appropriate statistical tests (eg, use of Bonferroni correction, longitudinal data analysis, adjustment only for a priori identified confounders)*

0	inappropriate statistics, extensive data dredging, or no information about appropriateness of statistics
1	moderately appropriate, though unsophisticated, statistics and/or moderate data dredging
2	fully appropriate statistics and minimal data dredging in primary findings

Item 18. Adequate sample size

0	inadequate justification and inadequate sample size
1	adequate justification or adequate sample size (e.g. more than 30 participants in each condition)
2	adequate justification and adequate sample size (e.g. more than 50 participants for each condition OR a priori calculation of sample size and this sample size or more recruited)

Item 19. Appropriate consideration of therapist and site effects

0	therapist and site effects not discussed or considered
1	therapist and site effects discussed or considered statistically
2	therapist and site effects discussed and considered statistically

Treatment assignment

Item 20. A priori relevant hypotheses that justify comparison group(s)

0	poor or no justification of comparison group(s)
1	brief or incomplete justification of comparison group(s)
2	full justification of comparison group(s)

Item 21. Comparison group(s) from same population and time frame as experimental group

0	comparison group(s) from significantly different population and/or time frame
1	comparison group(s) from moderately different population and/or time frame or it appears they are from the same population and time frame but no statistical analysis has been performed to confirm this.
2	comparison group(s) from same population and time frame

A rating of 2 requires;

- Participants recruited and received intervention at the same time AND
- Description of the demographics of each group including ethnicity and mean ages – clearly compared e.g. with percentages and/or in a table AND
- Statistical analysis performed on quantitative data that demonstrates no significant differences between the groups at baseline.

Item 22. Randomized assignment to treatment groups

0	poor (eg, pseudo-randomization, sequential assignment) or no randomization
1	adequate but poorly defined randomization procedure
2	full and appropriate method of randomization performed after screening and baseline assessment

A rating of 2 requires;

- Full description of the type of randomization procedure used (e.g. using specific software to randomly allocate)

Overall quality of study

Item 23. Balance of allegiance to types of treatment by practitioners

0	no information or poor balance of allegiance to treatments by study therapists (eg, therapy in experimental and control groups both administered by therapists with strong allegiance to therapy being tested in the experimental group)
1	some balance of allegiance to treatments by study therapists
2	full balance of allegiance to treatments (eg, therapies administered by therapists with allegiance to respective techniques)

A rating of 2 requires;

Evidence that therapist/s within all interventions (apart from waiting list) had extensive experience in the intervention/s they delivered OR it is stated that they had received specific training in the intervention being delivered (i.e. mindfulness practitioner). AND

- Therapists were not solely qualified in another intervention that was not being provided (i.e. a CBT therapist facilitating a mindfulness intervention)

Item 24. Conclusions of study justified by sample, measures, and data analysis, as presented (note: useful to look at conclusions as stated in study abstract)

0	poor or no justification of conclusions from results as presented or insufficient information to evaluate (eg, sample or treatment insufficiently documented, data analysis does not support conclusions, or numbers of withdrawals or dropouts makes findings unsupported)
1	some conclusions of study justified or partial information presented to evaluate
2	all conclusions of study justified and complete information presented to evaluate

Item 25. Omnibus rating: please provide an overall rating of the quality of the study:

24 items in total/score range 0-48

- 1 = exceptionally poor (0-7)
- 2 = very poor (8-14)
- 3 = moderately poor (15-21)
- 4 = average (22-29)
- 5 = moderately good (30-35)
- 6 = very good (36-42)
- 7 = exceptionally good (43-48)

Supplementary Material

Appendix F1

Full text articles excluded with reasons

MABIs for caregivers of people with dementia

Article	Reason study was excluded
Black et al. (2013)	Not a mindfulness or acceptance based intervention
Coogle, Brown, Hellerstein and Rudolph (2011)	Data overlapped with that of another study
Danucalov, Kozasa, Afonso, Galduroz and Leite (2015)	No measure of depression or caregiver burden
Danucalov et al. (2013)	Intervention did not include at least 50% of mindfulness or acceptance based principles or practices.
Garcia (2015)	No measure of depression or caregiver burden
Ho, Bloom, Vega and Pasinetti (2012)	This was a Conference paper
Ho et al. (2016)	No pre and post data was made available by study authors.
Hou et al (2013)	Caregivers of people with chronic conditions not specific to dementia
Innes, Selfe, Brown, Rose and Thompson-Heisterman (2012)	Intervention was not acceptance or mindfulness based.
Jain, Nazarian and Lavretsky (2014)	Intervention did not include at least 50% of mindfulness or acceptance based principles or practices.
Lavretsky et al. (2013)	Meditative practices were not deemed to be mindfulness based.
Macquez-Gonzalez, Romero-Moreno, and Losada, (2012)	Results were presented in a book chapter but full data was not made available.
Mcbee (2003)	A discussion/review paper not an empirical study
Pomykala et al. (2012)	Intervention was deemed not to be acceptance or mindfulness based.
Saavedra (2015)	No full text available, no author contact details found
Waelde, Thompson and Gallagher-Thompson (2004)	Intervention was not deemed to be mindfulness based.

Supplementary Material

Appendix G1

MABIs for caregivers of people with dementia

Reference list of full text articles excluded with reasons, not cited in text

Black, D. S., Cole, S. W., Irwin, M. R., Breen, E., St Cyr, N. M., Nazarian, N., Khalsa, D.S., & Lavretsky, H. (2013). Yogic meditation reverses NF- κ B and IRF-related transcriptome dynamics in leukocytes of family dementia caregivers in a randomized controlled trial. *Psychoneuroendocrinology*, 38(3), 348-355.

Coogle, C. L., Brown, K. W., Hellerstein, J. M., & Rudolph, A. (2011). *Mindfulness-Based Alzheimer's Caregiving: A Randomized Controlled Trial A Replication Report*. Retrieved 2/3/13 at [www. sahp. vcu. edu/ vcoa/ program/ reports/ pdfs/ aoa_ reporting .pdf](http://www.sahp.vcu.edu/vcoa/program/reports/pdfs/aoa_reporting.pdf).

Danucalov, M. A., Kozasa, E. H., Afonso, R. F., Galduroz, J. C., & Leite, J. R. (2015). Yoga and compassion meditation program improve quality of life and self-compassion in family caregivers of Alzheimer's disease patients: A randomized controlled trial. *Geriatrics & Gerontology International*, 17(1), 85-91.

Danucalov, M.A.D., Kozasa, E.H., Ribas, K.T., Galduróz, J.C.F., Garcia, M.C., Verreschi, I.T.N., Oliveira, K.C., Romani de Oliveira, L. & Leite, J.R. (2013). A yoga and compassion meditation program reduces stress in familial caregivers of Alzheimer's disease patients. *Evidence-Based Complementary and Alternative Medicine*, 2013, 513149

Garcia, E. (2015). *A mindfulness based dementia care pilot program: impact on caregivers' stress and compassion* (Doctoral dissertation). California State University: Stanislaus

MABIs for caregivers of people with dementia

Ho, L., Bloom, P. A., Vega, J. G., & Pasinetti, G. M. (2012). Exploring The Molecular Mechanisms Underlying The Efficacy of Mindfulness Based Stress Reduction In Alleviating Psychological Stress in Alzheimer's Disease Caregivers. *The FASEB Journal*, 26(1 Supplement), 846-1.

Ho, L., Bloom, P.A., Vega, J.G., Yemul, S., Zhao, W., Ward, L., Savage, E., Rooney, R., Patel, D.H. & Pasinetti, G.M. (2016). Biomarkers of Resilience in Stress Reduction for Caregivers of Alzheimer's Patients. *Neuromolecular Medicine*, 18(2), 177-189.

Innes, K. E., Selfe, T. K., Brown, C. J., Rose, K. M., & Thompson-Heisterman, A. (2012). The effects of meditation on perceived stress and related indices of psychological status and sympathetic activation in persons with Alzheimer's disease and their caregivers: a pilot study. *Evidence-Based Complementary and Alternative Medicine*, 2012.

Jain, F. A., Nazarian, N., & Lavretsky, H. (2014). Feasibility of Central Meditation and Imagery Therapy for dementia caregivers. *International Journal of Geriatric Psychiatry*, 29(8), 870-876.

Márquez-González, M., Romero-Moreno, R., & Losada, A. (2012). Caregiving issues in a therapeutic context: new insights from the Acceptance and Commitment Therapy approach In N. Pachana, K. Laidlaw & B. Knight (Eds.). *Casebook of Clinical Geropsychology: International Perspectives on Practice* (pp33-51).Oxford, UK: Oxford University Press.

McBee, L. (2003). Mindfulness practice with the frail elderly and their caregivers: Changing the Practitioner-Patient Relationship. *Topics in Geriatric Rehabilitation*, 19(4), 257-264.

MABIs for caregivers of people with dementia

Pomykala, K. L., Silverman, D. H., Geist, C. L., Voegel, P., Siddarth, P., Nazarian, N., St Cyr, N.M., Khalsa, D. S. & Lavretsky, H. (2012). A pilot study of the effects of meditation on regional brain metabolism in distressed dementia caregivers. *Aging Health, 8*(5), 509-516.

Saavedra, Y. (2015). *"All it takes is just 10 Minutes of Mindfulness Meditation": Providing an Educational Tool to Reduce Stress in Caregivers of persons who have Alzheimer's Disease, Through a Mindfulness Meditation Class in Peru.* (Doctoral dissertation, University of California, Davis).

Waelde, L. C., Thompson, L., & Gallagher-Thompson, D. (2004). A pilot study of a yoga and meditation intervention for dementia caregiver stress. *Journal of Clinical Psychology, 60*(6), 677-687.

Chapter four: Additional Methodology

Word count: 468

Chapter four: additional methodology

Random effects vs fixed-effect model

The thesis consistently conducted analyses under the random-effects model and not the fixed-effect model; including when ascertaining the overall combined effects, comparing the mean effect estimates between groups of studies (subgroup analysis) and when assessing the relationship between one or more covariates (moderators) and effect estimates. The decision to adopt the random-effects model for all analyses was made *a priori*. Some researchers (e.g. Hak, van Rhee & Suurmond, 2016; Zlowodzki et al., 2007) have suggested that this decision can be made following the assessment of heterogeneity (i.e. if no significant heterogeneity is present then analyses can be conducted under the fixed-effect model). However, many have argued that the decision to use either model is concept-driven not data-driven, and so insist that model selection should always be made *a priori* (Singh, 2017).

Either model assigns ‘weights’ to the effect sizes of individual studies depending on their level of precision and computes a ‘weighted mean effect size’. The fixed-effect model assumes that there is one true effect size that underlies all of the included studies, any differences between individual effect estimates are caused by within-study sampling error, and the weighted mean effect size is the estimate of this common effect (Borenstein, Hedges & Rothstein, 2009). Each study is assigned a weight entirely on the basis of the amount of information gathered; the weight is calculated as the inverse of the variance within the study.

In contrast, the random-effects model assumes that the true effect may or may not vary from one study to another, differences observed are due to within-study

Additional methodology

and between-study sampling errors, the included studies are a random sample of the relevant distribution of effects and the weighted mean effect size is the estimate of the mean effect in this distribution (Borenstein et al., 2009). Each study is assigned a weight based on the amount of information gathered and variance between studies; the weight is calculated as the inverse of the variance within the study and between the studies. Consequently, weights are often more balanced than those assigned under the fixed-effect model.

The fixed-effect model therefore makes different assumptions to the random-effects model about the nature of the studies, and these assumptions lead to different definitions for the combined effect, different mechanisms for assigning weights, and often different results. Borenstein et al. (2009) stated that the use of the fixed-effect model should be confined to reviews that include identical studies – those that have recruited individuals from one population and employed identical methods. Given that both of the meta-analyses within this thesis were conducted on a series of studies that were performed by different people at different locations and different times, effect estimates were likely to differ from study to study and hence analyses were computed under the random-effects model.

Chapter five: discussion and critical appraisal

Word count: 4922

Chapter five: discussion and critical appraisal

Summary of main findings

The thesis is comprised of two meta-analyses. The first meta-analysis included forty-three studies set across five of the seven continents, examining a combined total of 16 911 participants of diverse ages and relational statuses to care-recipients. The meta-analysis demonstrated that approximately 31.2% of informal caregivers of PwD experience depression and 49.3% perceive their caregiving role to be burdensome. Publication bias assessments suggested these results were robust – particularly the pooled depression prevalence estimate. There was, however, significantly high heterogeneity among the prevalence estimates, with the depression prevalence estimates differing according to the outcome measures used and the continent in which the study was conducted. However, even the lowest pooled prevalence estimate of depression (reported in Asian countries) was higher than that of the pooled prevalence estimate of depression (assessed via self-report measures) among older adults in Asia found within the meta-analysis of Luppá et al. (2012). Rates of depression were found to be 1.45 times higher in female compared to male caregivers. However, rates did not significantly differ between spousal and non-spousal caregivers. The second meta-analysis included twelve studies involving a total of 321 caregivers of diverse ages. The results suggested that MABIs are largely effective at reducing depressive symptoms and moderately effective at reducing caregiver burden, with these results largely maintained at follow-up. The majority of the findings were shown to be robust in the context of publication bias. Overall the findings indicated that MABIs may be at least as effective as cognitive-behavioural therapy (CBT). However, similar to the first meta-analysis, significantly moderate to

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high heterogeneity amongst almost all of the effect sizes was observed. Meta-regression analyses did not reveal any significant moderators for the pre-post depressive symptoms effect sizes, although the analyses may have been underpowered.

Key strengths of the thesis

A key strength of the thesis is that it focussed on a globally pressing issue - dementia. Emphasised throughout, the number of PwD is rising each year and the economic strain dementia places on governments is colossal, particularly in health and social care costs (Leungo-Fernandez, Leal & Gray, 2015). Caregivers of PwD save economies worldwide billions of pounds every year by helping reduce and delay rates of transition into care homes (Brodaty & Donkin, 2009). The thesis was able to further the evidence base for the negative psychological impacts of the dementia caregiving role and the type of interventions that may be effective at reducing these.

The thesis is novel. In terms of the first meta-analysis, the authors were not aware of any previous meta-analyses that had estimated the prevalence of caregiver burden among informal caregivers of PwD and therefore this was the first meta-analysis to do so. In terms of the second meta-analysis, the majority of previous reviews focussed on psychosocial interventions or cognitive behavioural therapy for informal caregivers of PwD (e.g. Cooke, McNally, Mulligan, Harrison & Newman, 2001; Dam, de Vugt, Klinkenberg, Verhey & van Buoxtel, 2016; Pinquart & Sörenson, 2006; Gallagher-Thompson & Coon, 2007; Kinnear, 2012). One review had explored the effectiveness of meditation based interventions for informal caregivers of PwD (Hurley, Patterson & Cooley, 2014), and another mindfulness-

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based interventions for informal palliative caregivers (Jaffray, Bridgman, Stevens & Skinner, 2016). However, the first included meditation exercises that were not mindfulness-based, the second included caregivers of people without dementia, and both were qualitative in nature. No review had therefore quantified the size of the effectiveness of MABIs for informal caregivers of PwD and therefore the second meta-analysis pioneered this.

The third strength relates to the second, the methodology used within the thesis - meta-analysis. Rosenthal and DiMatteo (2001) posit that meta-analysis allows researchers to arrive at conclusions that are more accurate and more credible than can be presented in any one primary study or in a non-quantitative, narrative review. Small individual studies, such as many of those included in the second meta-analysis, can lack the statistical power to uncover significant results (especially if the effect size is not large) and this can often mislead researchers into concluding the value of the findings based upon their non-significance. Quantitatively combining the outcomes of small or inconclusive studies prevents researchers from relying on the significance result of any one finding as a measure of its value, and improves the power to detect significant results (Ioannidis & Lau, 1999) as repeated results in the same direction across several studies, even if not one is significant, are much more powerful evidence than a single significant result (Rosenthal & Dimatteo, 2001). Although it must be noted that Jackson and Turner (2017) argue that for random-effects meta-analyses, where between-study variance is included and there is a need to estimate this parameter, a minimum of five studies must be entered into the analysis to achieve this increased power. When studies yield varying results, qualitative or narrative methods may attempt to list and describe such differences which can be confusing and the overall message from the data can remain unclear

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(Rosenthal & Dimatteo, 2001). Whereas, a meta-analysis can synthesise these findings to provide an overall estimate and can help resolve inconsistencies in the research findings by exploring moderator variables (Stone & Rosopa, in press). For instance, the first meta-analysis was able to identify that depression prevalence estimates differed by the type of instrument used and the continent the study was conducted in. Furthermore, in contrast to a systematic or narrative review, a meta-analysis can help detect and adjust for publication bias (the notion that studies with significant results are more likely to be published than those with non-significant findings).

The thesis is comprehensive. Each meta-analysis searched six electronic databases (obtaining published and unpublished articles), and hand searched the reference lists of relevant reviews and meta-analyses and the included studies. The searches resulted in over 8000 articles for both meta-analyses, all of which were meticulously screened. Although funnel plots and the trim-and-fill method can estimate the number of potentially missing studies from the analysis, it must be acknowledged that these are estimations and not truths. At least, the sensitivity of the searches demonstrates that the meta-analyses attempted to capture the majority of studies that met eligibility criteria, which is vital given that failure to do so can lead to erroneous conclusions (Haidich, 2010).

Finally, a particular strength of the first meta-analysis is the number of studies included in the analysis of the prevalence of depression, and the strength of this finding in the context of publication bias. Although a meta-analysis can arguably be conducted on as little as two studies, the more studies that meet criteria and are statistically combined, the more likely it is that the meta-analysis is sufficiently powered (Valentine, Pigott & Rothstein, 2010).

Key limitations of the thesis

The thesis found moderate to high heterogeneity amongst almost all of the effect sizes; heterogeneity being the level of dispersion of effect sizes from study to study, determined throughout by the chi squared statistic (Higgins & Thompson, 2002) and I squared statistic (I^2 ; Higgins, Thompson, Deeks & Altman, 2003). As discussed previously in the additional methodology chapter, the authors expected significant heterogeneity of effect sizes to be present given that studies differed according to who they were performed by, where and how they were conducted and the time period in which they were conducted in. However, the authors did not expect the heterogeneity of most of the effect sizes to be substantial.

Some researchers have tried to ascertain whether there is an ‘acceptable’ degree of heterogeneity to which the summary effect can then be reliably reported (Higgins, 2008). When heterogeneity is substantial (over 75%) some researchers have suggested that authors should avoid pooling the results and presenting a summary effect (Thompson and Pocock 1991). Instead, if all effect sizes are in a positive direction and the pooled confidence interval does not include zero, authors could conclude that there was a general ‘positive effect’, providing that sufficient studies and subject numbers were present (Haidich, 2010). Others have indicated that authors should report both the summary effect and heterogeneity of effects and interpret the summary effect ‘with caution’ (Greenland, 1994). Higgins (2008) however stated that:

“Any amount of heterogeneity is acceptable, providing both that the predefined eligibility criteria for the meta-analysis are sound and that the data are correct” (Higgins, 2008).

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Although Higgins (2008) does not specify what “sound” means, the authors are confident that the eligibility criteria for both meta-analyses were theoretically acceptable, clear and can be replicated, and were in line with the aims of the meta-analyses, and that the data collected and analysed were correct. The authors therefore justifiably reported the summary effects and the findings of moderate to high heterogeneity of effect sizes both within the main manuscripts and the abstracts. Higgins (2008) and Zlowodski et al., (2007) suggested that authors must also look for explanations of heterogeneity by conducting subgroup analyses and/or meta-regression. The first and second meta-analysis attempted to uncover moderating factors using both of these methods. Overall, the findings of significant moderate to high heterogeneity of effect sizes may pose as a limitation of the thesis results in terms of their generalizability. However, in line with Higgins’ (2008) recommendations, findings of heterogeneity among effect sizes were adequately addressed by reporting both the summary effects and findings of heterogeneity, and exploring the possible factors contributing towards these.

Another potential limitation of the thesis is the quality of the included studies. Eighteen of the 43 included studies within the first meta-analysis were rated as ‘high risk’ and six of the 12 included studies within the second meta-analysis were rated as ‘very poor’. The ‘garbage in, garbage out’ metaphor refers to the idea that if a meta-analysis includes many low-quality studies, then fundamental error in the individual studies will be carried across to the meta-analysis where the errors may be harder to identify (Borenstein et al., 2009). To address this, both meta-analyses conducted moderator analysis to determine whether the variations in study quality were related to the size of the effects. In fact, study quality was not found to be a significant moderator of the burden or depression prevalence estimates or the pre-post burden or

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depression effect sizes. However, that said, it is possible that the second meta-analysis was underpowered to detect significance in this analysis.

An aspect of study quality that must be mentioned is the degree to which studies reported on the diagnoses of the care-recipients and the procedures or tools used to ascertain these. Only 52% and 55% of the 43 included studies in the first meta-analysis reported information on the diagnoses of the care-recipients and the procedures or tools used to ascertain these, respectively. Likewise, only 33% and 25% of the 12 included studies in the second meta-analysis reported information on the diagnoses of the care-recipients and the procedure or tools to ascertain these, respectively. The second meta-analysis acknowledged that one study included two caregivers of people without dementia and a sensitivity analysis was conducted. However, the lack of information reported overall on the diagnoses and diagnostic procedures demonstrates a significant limitation of the thesis; neither meta-analysis can reliably state that the overall findings are derived from studies in which all caregivers were caring for someone with a formal diagnosis of dementia. Given the experiential differences between caregivers of individuals with and without dementia this would appear an extremely important limitation.

Although previously defined as a strength of the thesis, many have criticised the use of meta-analysis and therefore it is discussed here as a potential limitation. One of the primary arguments has been that it is synonymous to combining “apples and oranges”; it combines studies that are not identical (i.e. have varying measurements and methodologies) and therefore it is like taking apples and oranges and averaging such measures as their weights, sizes, flavours, and shelf lives (Hunt 1997). Researchers who strongly align themselves with this argument, may criticise the second meta-analysis as it combined studies that used Mindfulness Based Stress

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Reduction (Kabat-Zinn, 1990), Mindfulness Based Cognitive Therapy (Segal, Williams & Teasdale, 2002), Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 1999) and Dialectical Behaviour Therapy (Linehan, 1993). In addition, these interventions varied greatly, such as in the number of sessions provided and the overall contact time. In accordance with this criticism, as opposed to conducting a meta-analysis combining MABIs, the authors could have explored the effectiveness of a particular MABI at an individual study level. For example, by working with a local dementia service to recruit and provide an acceptance and commitment therapy group and assessing the outcome of this group using depression and burden measurements. However, Borenstein et al., (2009) and Rosenthal and DiMatteo (2001) argue that meta-analyses almost always aim to answer a broader question and combining apples and oranges is sensible if one wants to generalize about fruit, and that studies that are exactly the same in all respects are limited in generalizability. This supports the appropriateness of the second meta-analyses in answering the broader question of the effectiveness of all MABIs for informal caregivers of PwD.

Finally, some researchers have criticised the use of meta-analyses on pre-post effects (as performed in the second meta-analysis within the thesis). They have argued that such meta-analyses should be avoided, partly because the effects are influenced by natural processes and characteristics of the patients and settings, and these cannot be discerned from the effects of the intervention (Cuijpers, Weitz, Cristea & Twisk, 2017). The thesis authors acknowledged that combining post treatment-control effects is more reliable and enables a meta-analysis to conclude the effectiveness of an intervention relative to its absence (Hollon & Wampold, 2009). Hence, the second meta-analysis included the synthesis of post between-group effects on depressive symptoms as well as the pre-post effects on depressive

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symptoms. Furthermore, Borenstein et al. (2009) provide clear guidelines on how to most reliably conduct meta-analysis on pre-post effect size data, and given that the field of research of the second meta-analysis is in its infancy, limiting the eligibility criteria to randomized controlled trials would have produced an extremely small number of studies. It therefore appeared important to explore whether these interventions are beneficial for informal caregivers of PwD, even if the review could not state with certainty that it was elements of the interventions that produced such beneficial changes.

Links to theory and research

There are two prominent models that conceptualised the development of significant burden among informal caregivers of PwD (Poulshock & Deimling, 1984; Pearlin, Mullan, Semple & Skaff, 1990). There is also a model that focussed on the moderating factors (or risk factors) for depression among informal caregivers of PwD, but did not conceptualise the longitudinal development of depression (Dilworth-Anderson & Anderson, 1994; and the adapted version by Williams, 2005). Another model focused on the moderating factors for significant burden and highlighted the interaction between burden and health (including depressive symptoms) among informal caregivers of PwD, but similarly did not conceptualise the longitudinal development of burden/emotional health difficulties (Knight & Sayeh, 2010). There did not, therefore, appear to be a model that combined the development of, risk factors for, and the relationship between, depression and burden among informal caregivers of PwD. In order to consider the findings in a wider context and explore a potential critical role of MABIs in maintaining the wellbeing of caregivers the author developed such a model. The model was based on previous research, the models discussed above alongside the diathesis-stress model (Ingram et

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al., 2011), and the thesis findings of the prevalence of depression and burden, the rates of depression among female compared to male caregivers, the rates of depression across continents, and the observed effects of MABIs on depressive symptoms and burden. Please refer to Fig 1.

Diathesis-stress

The thesis discovered that approximately 50% of all informal caregivers of PwD perceive their caregiving role to be burdensome and 31.24% experience depression. The depression prevalence estimate is substantially higher than the global prevalence of depression (4.4%; WHO, 2017), the prevalence of depression among older adults (Li, Zhang, Shao, Qi & Tian, 2014; Luppá et al., 2012) and the prevalence of depression among caregivers of people with cancer (Krebber et al., 2014). These differences in prevalence estimates are in line with previous meta-analyses that found increased depressive symptoms among caregivers of PwD compared to people who were not caregivers (Pinquart & Sörensen, 2003) and increased mental health difficulties among caregivers of people with dementia compared to caregivers of people without dementia (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999).

The diathesis-stress perspective (Ingram, Atchley, & Segal, 2011) posits that all individuals have varying degrees of vulnerability or “diathesis” to experiencing psychological difficulties, and it is from the presence of a stressful life event that psychological difficulties may arise. Caregiving for someone with dementia has been considered a chronic stressful situation (Romero-Moreno, Márquez-González, Losada, Gillanders & Fernández-Fernández, 2014). Adopting the caregiving role has been likened to taking on a career in that it has a beginning, multiple phases,

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transitions, and changes, and has an end point (Aneshensel, Pearlin, Mulan, Zarit, & Whitlach, 1995). A significant proportion of caregivers of PwD assist with a large variety of care tasks, experience employment complications and limited time for leisure and social activities due to caregiving responsibilities, and an estimated 28% provided from 25 hours of care to ‘constant care’ per week (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999). A dementia diagnosis also threatens social inclusion and the family’s finances (Poz, 2014). In addition, caregivers must cope with the fact that their loved one’s condition will worsen and they may die as a result of the disease, which reduces or eliminates the idea or visibility of positive long term effects of caregiving (Clipp & George, 1993). The higher rates of depression prevalence found among this population therefore support the concept that the caregiving role acts as a stressful life event that triggers emotional difficulties.

Risk factors

In accordance with the diathesis-stress perspective (Ingram et al., 2011), the impact that dementia and the caregiving role has on the caregiver’s perception of burden and emotional health may not only be dependent on their diathesis but on a number of risk factors. The thesis discovered higher rates of depression among female caregivers compared to male caregivers, supporting the findings of Sallim, Sayampanathan, Cuttilan, & Ho (2015) and the risk factor of ‘gender’ for depression suggested in the model of Williams (2005). The thesis, however, found no significant difference between the rates of depression among spousal and non-spousal caregivers. In fact, three of the six studies found higher rates of depression among non-spousal caregivers compared to spousal caregivers of PwD. These findings did not support those of Sallim et al. (2015), nor the risk factor of ‘relationship type to the care-recipient’ for depression suggested in Williams’ model

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(2005). Some research has indicated that it may not be the type of relationship that poses a risk for depression but the caregiver's perception of the quality of the relationship prior to and following the onset of dementia. For example the effect of relationship 'closeness', sometimes conceptualized as the quality of the emotional bond between the caregiver and care recipient (Whitlatch, et al., 2001), and 'intimacy' on depression among informal caregivers of PwD has been investigated in several studies. Kramer (1993) and Williamson and Schulz (2001) found closer relationships prior to the onset of dementia predicted lower levels of depressive symptoms. Similarly, Fauth et al. (2012) found that higher baseline levels of 'closeness' predicted lower baseline levels of depressive symptoms, although closeness was not related to change in depressive symptoms over time. Furthermore, Morris, Morris and Britton (1998) found caregivers with lower levels of intimacy prior to and following the onset of dementia had higher levels of depressive symptoms. Morris et al. (1998) also found caregivers who experienced a greater loss of intimacy as a result of the dementing illness had higher levels of depression. Although this finding was arguably not supported by Fauth et al. (2012) who found that changes in closeness, comparing closeness prior to and following the onset of dementia, were not associated with baseline depressive symptoms or changes in depressive symptoms over time.

Research has also indicated that a caregiver's satisfaction with their relationship prior to the onset of dementia may be related to the degree of perceived burden; caregivers with high premorbid relationship satisfaction have reported lower levels of burden (Steadman, Tremont & Davis, 2007).

Reviews have identified other risk factors for burden that are detailed in Williams' (2005) model, including socio-demographic variables of the caregiver

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such as education level, income, gender and patient characteristics such as behavioural disturbances and dementia severity (Etters, Goodall & Harrison, 2008; Chiao et al., 2015). Identified within the model of Knight and Sayeh (2010) and highlighted in the study of Williams (2005) is the impact of cultural factors, such as values of obligation. Indeed, the thesis discovered that the prevalence of depression differed according to the continent in which the study was conducted, with Australia yielding the highest pooled prevalence estimate. This finding is consistent with previous research, where depression was discovered to be a predictor of suicidal ideation in a sample of informal caregivers of PwD, and individuals recruited in Australia were found to have a higher prevalence of suicidal ideation than those recruited within Europe (O'Dwyer, Moyle, Zimmer-Gembeck & De Leo, 2016; Joling, O'Dwyer, Hertogh, & van Hout, 2018).

Another risk factor identified by Knight and Sayeh (2010) is a caregiver's 'coping style' - the ways in which the caregiver responds to their internal and external experiences. Supporting an ACT perspective of suffering, research has revealed that caregivers of PwD can often engage in strategies that attempt to avoid the experience of difficult emotions and the acceptance of difficult caregiving situations. The more these strategies are used, the more depressive symptoms are experienced (Williamson & Schulz, 1993; Spira et al., 2007). High levels of rumination and cognitive fusion have also been found to be associated with increased experiential avoidance, depression and anxiety in this population (Romero-Moreno, Márquez-González, Losada, Fernández-Fernández & Nogales-González, 2014). The thesis found mindfulness and acceptance based interventions (MABIs) to be largely effective at reducing depressive symptoms and moderately effective at reducing burden among informal caregivers of PwD. Although it was not possible to

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determine the mechanisms of change of these interventions, the findings may suggest that, because all MABIs aim to decrease experiential avoidance and increase present moment awareness (mindfulness) and acceptance, they are effective at reducing depressive symptoms in this population.

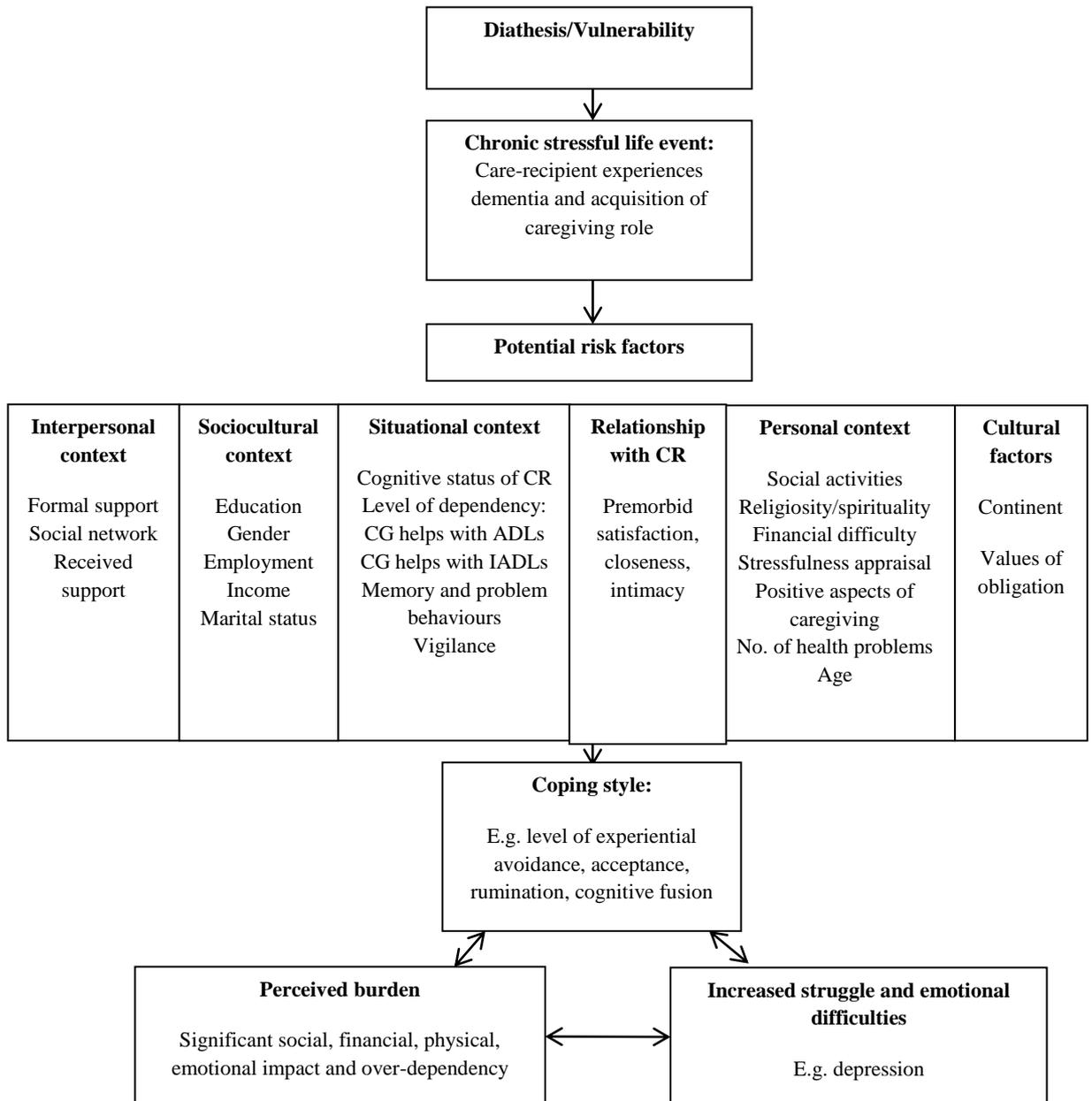


Fig 1. A conceptualisation of emotional difficulties and burden among informal caregivers of PwD based upon key research findings of the associations between risk factors, coping styles and burden and emotional difficulties, the current thesis

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findings, and the models of Williams (2005), Poulshock & Deimling (1984), Pearlin et al. (1994), Knight and Sayeh (2010) and Ingram et al. (2011).

Association between depressive symptoms and burden

In line with Knight and Sayeh (2010), the author's model (Fig 1.) includes the relationship found between depressive symptoms and burden – research revealing that depressive symptoms and burden are positively correlated with one another (Epstein-Lubow, Davis, Miller & Tremont, 2008; Medrano, Rosario, Payano & Capellan, 2014)

Future research

Within the first and second meta-analyses the authors suggested several future research directions based upon the findings. There are two that appear most pertinent. The first is the need for higher quality studies that explore the prevalence of depression and/or burden among informal caregivers of PwD, or the effectiveness of a MABI for depressive symptoms and/or burden. The second meta-analysis revealed that there is a clear lack of randomized controlled trials (RCTs) in this field of research. It is well understood that RCTs are of a higher quality than before-and-after designs and the most reliable way of assessing the effectiveness of an intervention (Hollon & Wampold, 2009). The study did not find significant heterogeneity among the post between-group effect sizes for depressive symptoms and this may be due to the fact that only seven fairly small studies were included within this analysis. Further RCTs into the effectiveness of MABIs for this population could enable a future meta-analysis to explore possible heterogeneity in order to uncover the most effective ways of delivering these interventions.

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The majority of studies in both meta-analyses achieved poor ratings on similar quality aspects. The areas of study quality that require improvement (both for prevalence studies and MABI studies) include: (1) details of the history of psychiatric problems of the informal caregivers (2) descriptions of participation and response rates (3) comparisons of respondents/participants and non-respondents/participants (4) details of the diagnoses of the care-recipients (5) details of the procedures used to diagnose dementia. In terms of exploring the effectiveness of a MABI, studies should also strive to include a greater number of participants (e.g. over 100) and a measure of treatment adherence. Without such a measure, there is a lack of evidence that the treatment being studied is the treatment being delivered.

The second suggested research direction that appears most important is the need for studies into the prevalence of depression among informal caregivers of PwD conducted in the continents of South America and Africa. The first meta-analysis revealed that the prevalence of depression differed according to the continent in which the study was conducted. However, as the review only found one South American study that reported on the prevalence of depression this could not be entered into the subgroup analysis, and no studies were found that were conducted in Africa. Studies suggest that there is a lack of mental health research from low- and middle-income countries including Latin America and Africa (Sharan et al., 2009) and therefore the results of the current thesis are perhaps unsurprising. Future studies into the prevalence of depression among informal caregivers of PwD within these continents, could enable a meta-analysis to more reliably estimate the global prevalence of depression among informal caregivers of PwD. Furthermore, if the prevalence of depression among this population in Africa or South America was significantly different to each other or the other continents, it could shed light on the

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potential cultural protective or risk factors for depression and so inform the hypothesised model of emotional difficulties presented in Fig 1.

Clinical implications

The first meta-analysis found 31.24% of informal caregivers of PwD experience depression and 49.26% perceive their caregiving role to be burdensome. These findings therefore strongly advocate the need for dementia services and/or mental health services to provide interventions that are effective at reducing burden and depressive symptoms within this population. The second meta-analysis is able to add towards the evidence base of therapies that are effective at reducing these difficulties and can inform NICE (2006) and other dementia guidelines. The meta-analysis provides evidence towards the appropriateness of dementia services developing and providing MABIs to this population, or signposting informal caregivers to local mindfulness groups. Although, it must be borne in mind that ten of the included studies that provided a MABI in a group format included *only* caregivers of PwD (as per the eligibility criteria). It may be important for caregivers to attend mindfulness groups that are delivered solely to caregivers of PwD - as being with other people experiencing similar challenges could help reduce any perceived stigma associated with dementia and caregivers may be more likely to attend a group where they believe others will understand their experiences (Alzheimer's Association, 2018). Locating such groups through local charitable organisations may pose a challenge for clinicians; therefore increasing the rationale for the provision of MABIs within clinical dementia services.

Conclusion

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It is vital for the economy that individuals with dementia are delayed from transitioning into care homes for as long as possible, and therefore it is essential that informal caregivers of PwD are able to effectively maintain their caregiving role. The thesis discovered that a significant proportion of informal caregivers of PwD experience depression and perceive their caregiving role to be burdensome. The prevalence of depression differed according to the instrument used and the continent in which the study was conducted. Overall, the findings suggest that there is a great need within this population for interventions that are effective at reducing burden and depressive symptoms. Previous research suggests that reducing these difficulties could enable caregivers to effectively maintain their caregiving role and prolong the transition of the care-recipient to a care home, and could prevent the emergence of post-death psychiatric morbidity. The thesis discovered that MABIs are acceptable for informal caregivers of PwD, and were found to be largely effective at reducing depressive symptoms and moderately effective at reducing burden among this population, with these effects largely maintained at follow-up. Although there was significantly moderate to high heterogeneity amongst almost all of the effect sizes, the primary findings indicate that MABIs are beneficial for this population and support the development and delivery of MABIs for informal caregivers of PwD within clinical dementia services. There is a need, however, for higher quality research to improve the robustness of the evidence bases and research from low- and middle-income countries.

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